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Meaning-making processes among bereaved mothers who have lost a child to cancer

By

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of a degree of Master of Social Science in Clinical Psychology

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DECLARATION

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signature:.

Signed by candidate

Date:

University of Cape Town

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Finally, my therapist for showing me how to keep the memory of my brother 'alive,' and for believing in my ability and capacity to undertake a research project so closely related to personal experience.

DEDICATION

This study is dedicated to my late brother Evan, who died from leukemia at the age of nine and a half years. It has been an ongoing struggle for my parents to make sense of his death, and cope after their loss. Bereaved mothers in this study openly and generously tell their story, and in doing so, keep the memory of their child 'alive.' My late brother's young life will not be forgotten for as long as I live. He only dies, the moment myself, and my family stop remembering and speaking about him...

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ABSTRACT

The loss of a child constitutes a crisis of meaning, as prior meaning structures and fundamental assumptions about the world are shattered, and the natural order of life and death is undermined. Traditional models of mourning, premised on Freud's 'grief work' approach, do not address the concept of meaning-making (cognitive mastery and renewed purpose) during the grieving process, and only recently have theoretical models begun to recognize the importance of meaning-making in adjustment post-loss.

Grounded theory analysis of semi-structured interviews was employed in order to learn how ten bereaved mothers, ranging from thirty-five to seventy-six years of age make sense of, and cope after, losing a child to cancer. Results demonstrate that meaning is made by remaining connected to the deceased child, having contact with people and/or organizations, engaging in fulfilling activities, changing religious and/or spiritual beliefs, seeking professional help, and perceiving oneself as positively growing from the trauma. Child death due to cancer causes distress in itself, is particularly difficult to make sense of, and creates ongoing familial relationship difficulties. The results also highlight the individualistic nature of the grieving process, and that renewed purpose in life can be achieved without necessarily having made sense of certain questions surrounding the comprehensibility of losing a child to cancer.

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CHAPTER ONE

INTRODUCTION

“When a love tie is severed, a reaction, emotional, behavioural, cognitive, spiritual and physical is set in motion, which we call grief” (Parkes, 1972, p. 11). However, the loss of a child *“elicits the most profound bereavement”* (Staudacher, 1987, p. 111), and is considered to be the most traumatic and grievous of losses (Miles, 1985; Sanders, 1980; Videka-Sherman, 1982). Grief that results from such a loss is complex and intense, affecting our entire being (Tatelbaum, 1997). It has been argued that the loss of a child results in a more profound collapse of prior fundamental assumptions and meanings than is the case with other traumas or bereavements (Miles & Crandall, 1983). An entire collection of core beliefs, values, and norms about the way the world should be are called into question (Braun & Berg, 1994). The internal world of the bereaved is thrown into a state of turmoil and collapse, because the very assumptions that had provided psychological stability and coherence are recognised as obsolete and insufficient in coping in the aftermath of such a loss (Janoff-Bulman, 1992; Parkes, 1975; Thompson, 1981).

The loss of a child evokes the highest intensities of bereavement and the widest range of reactions because it is not expected for children to die (Staudacher, 1987). The natural order is that parents precede their child’s death. Parents take for granted that children will outlive them (Gorer, 1965; Rosen, 1988). Therefore, when a child dies, it feels like an untimely unnatural act (Rando, 1986), as parents readjust to a new and seemingly illogical reality (Staudacher, 1987).

However, little empirical research has been published regarding parental bereavement, particularly how bereaved parents experience and deal with the loss of a child to cancer. Childhood death due to a malignant disease, such as cancer, differs from other types of parental bereavement in that anticipating a pending death of a child can be distressing in itself (Attig, 1996; Norris & Murrell, 1987). Not only do parents have to witness their child suffer from a protracted medical illness (Worden, 2003), which very often follows a

progressively deteriorating course (Taylor, 1983), and face a long series of intensive medical treatments (Becvar, 2001) but they also have to contend with financial costs, and a prognosis that is uncertain, as well as perhaps needing to prepare funeral arrangements in advance, and discuss the nearing death with the sick child (Koocher, 1986).

Exploration of how bereaved mothers, in particular, make sense of, and cope after, this type of loss needs to be conducted, as men and women differ in terms of grieving responses and coping styles (Schwab, 1996; Doka & Davidson, 1998) and empirical research illustrates that bereaved mothers are more at risk than bereaved fathers of developing a mental illness (Li, Laursen, Precht, Olsen & Mortensen, 2005).

For nearly a century, bereavement theorists have assumed that working through grief, or 'grief work,' is necessary in order to recover from, and fully resolve, a loss. The eventual objective of the grieving process has been understood as the severing of the attachment bond to the deceased (Bonanno & Kaltman, 1999). Despite the historical dominance of the grief work perspective in the bereavement literature, there is an absence of empirical evidence or support for this view (M. Stroebe & W. Stroebe, 1987), thus creating a theoretical vacuum and leaving the bereavement field without a clear guiding theoretical base (Bonanno & Kaltman, 1999). Traditional models of mourning, which have largely been conceptualised out of Freud's (1917/1957) psychoanalytic model of mourning, do not address the concept of meaning-making during the grieving process.

Most of the research findings on meaning-making have emerged from trauma research and are viewed through the lens of trauma theory. Meaning-making is considered to be an essential and integral part of the adjustment process after a significant trauma (Frankl, 1986; Janoff-Bulman, 1992; Miles & Crandall, 1983; Neimeyer, 2001; Rando, 1986; Taylor, 1983; Tedeschi & Calhoun, 1995; Zoellner & Maercker, 2006). The role of meaning-making has also been recognised in recent bereavement literature. For example, Worden (2003) has refined his model of mourning, which he developed in earlier editions, in order to account for the meaning-making process whilst grieving. Bereavement researchers have in the past neglected work on psychological trauma, in

spite of the fact that loss and trauma are inextricably linked (Figley, Bride & Mazza, 1997). According to Wheeler (2001), *“the meaning-making process is an important aspect of readjustment and should be considered a vital component of grief counseling”* (p. 64).

1.1 Aims of the Study

This study aims to contribute to our knowledge of the bereavement process, and particularly the role of meaning-making in this process, by conducting a qualitative study with mothers who have lost a child to cancer. It is interested in evaluating the usefulness of traditional models of bereavement as opposed to more recently emerging models of mourning that emphasize the importance of meaning-making.

1.2 Structure of Dissertation

The dissertation is structured as follows.

Chapter two provides a review of the relevant literature. This chapter incorporates definitions of key terms, an overview of theoretical models of mourning and an evaluation thereof, a section on complicated bereavement and anticipated bereavement, an overview and evaluation of the empirical research generated on parental bereavement, current theories linking parental bereavement and meaning-making, and a review of the empirical research conducted on meaning-making after trauma and after parental bereavement.

Chapter three presents the methodology used in the current study. This chapter outlines the research aim, study design, sample, instruments, procedure, and data analysis employed. This is followed by a discussion of ethical considerations, which includes aspects such as informed consent, confidentiality, risks and benefits to participants, and of reflexivity issues in the research process.

Chapter four discusses and integrates the results that emerged from the qualitative analysis of the data with regards to how bereaved mothers make sense of, find meaning

in, and cope after, the loss of a child to cancer. Central themes are highlighted, and then located within the bereavement and trauma literature, as well as within empirical research on meaning-making after parental bereavement.

The concluding chapter contains a summary of the main findings, a discussion of the limitations and significance of this study, and a consideration of the implications of the findings for future research and clinical practice.

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CHAPTER TWO

LITERATURE REVIEW

This chapter begins with definitions of fundamental terminology, followed by a discussion of the various theoretical models of mourning, as well as an evaluation of those models. Included is a separate section on complicated bereavement and anticipated bereavement. Thereafter, the empirical research on parental bereavement is reviewed. After that, the concept of meaning-making is explained, and an overview of the empirical research conducted on meaning-making after trauma, and after parental bereavement, is presented.

2.1 *Definition of Terminology*

From the outset, it is necessary to define the key terminology repeatedly employed in the literature to be reviewed: grief, mourning, bereavement, and grief work. Meaning-making will be discussed later, as definitions of this concept are still being developed. For the purposes of this dissertation, the loss discussed will be the loss of life, that is, the death of a beloved individual.

Grief is the emotional response to loss (Stroebe & Stroebe, 1987), which includes disorganized behaviours and distressed feelings, such as sorrow, hurt, anger, guilt and confusion (Cavanaugh & Blanchard-Fields, 2002; Macnab, 1989). Thus, “*grief indicates the experience of one who has lost a loved one to death*” (Worden, 2003, p. 10). Cook and Dworkin (1992) offer a more complex psychological definition of grief, stating that it is the intrapsychic process of regaining equilibrium after a loss and requires re-organization on both emotional and cognitive levels.

Mourning is the public expression of grief (Cook & Dworkin, 1992), or the process of adapting after a loss (Worden, 1991), which is highly influenced by culture (Barlow & Durand, 1999; Rosenblatt, 1988; Rynearson, 1987; M. Stroebe, W. Stroebe, K. Gergen & M. Gergen, 1992). A distinction can therefore be made between grief and mourning. Grief refers to the personal experience of a loss (Worden, 2003), whereas mourning is the

culturally approved behavioural manifestations of the feelings of grief (Cavanaugh & Blanchard-Fields, 2002; Kastenbaum, 1986). For example, in some ethnic groups mourning may involve wearing black, attending funerals and observing an official period of grief; for others the mourning process might manifest differently (Cavanaugh & Blanchard-Fields, 2002).

Bereavement is defined as the general state or condition that results from having experienced a significant loss through death (Cook & Dworkin, 1992). Reference is made to those who are experiencing this general state of being as the bereaved (Macnab, 1989).

According to Stroebe (1992) and Attig (1996), 'grief work' is an active cognitive process involving confrontation with, and restructuring of, thoughts about the deceased, the experience of loss, and the changed world within which the bereaved now lives. The notion of 'grief work' will be expanded upon further when discussing the various models of mourning.

2.2 Models of Mourning

Bereavement theorists have viewed the mourning process in various ways, primarily as phases, tasks and stages. These theories are reviewed below.

2.2.1 Phases

Freud (1917) conceived of the mourning process as consisting of three distinct phases, which the bereaved individual needs to work through and complete.

The first phase includes the loss of the capacity to invest attachment or energy in other areas of life, as a result of losing a loved person. This initial phase of grief is characterised by shock and numbness in conjunction with disbelief and denial. The griever tends to feel disorganized, confused, motionless, helpless and bewildered by the impact. Furthermore, feelings of vulnerability may urge the mourner to seek protection by way of isolation and withdrawal.

The second phase involves the withdrawal of energy into the self, so reorganization can take place, a process of decathexis. This middle phase of grief is characterised by a period of intense 'grief work' where the pain of separation is experienced. During this phase, griever tend to yearn for the situation to be as it was prior to the loss. Bereaved individuals want to undo what has happened and return to the pre-grief state. Grievers are inclined to engage in fantasies of alternatives that may have prevented the loss.

The third phase entails a gradual reinvestment of energy into new objects, people or activities, a process of re-cathexis. This last phase of grief is a period of reintegration. The griever no longer experiences acute physical and/or emotional turmoil. The sadness does not disappear completely and certain triggers may stimulate a reminder or memory, but eventually the sadness and memories recede into the background. The griever begins to develop a renewed interest in the external world, and relief may be felt as the pain subsides. The bereaved person begins to move ahead with his/her life and the present concerns of life become the foreground on which to focus.

The correlation of bereavement with work can be traced to the phrase 'grief work,' coined by Freud (1917/1957) to describe the painful process where the ultimate objective is the severing of the attachment bond to the deceased love object. 'Grief work' gradually allows the ego to free its investment in the lost love object. According to Freud (1917/1957), grieving is essentially a private or intrapsychic process. Initially, the mourner clings so intensely to the lost object that *"a turning away from reality ensues"* (p. 154). However, as time passes the mourner gradually reviews *"each single one of the memories and hopes which bound the libido to the object"* until *"detachment of the libido from it [is] accomplished"* (p. 154).

According to Becvar (2001), *"the inability to complete this process of energy withdrawal in an appropriate and timely manner was indicative of pathology"* (p. 37). Bonanno and Kaltman (1999) comment on Freud's model of mourning, stating that the normal grieving process may be transformed into complicated or pathological mourning, as a result of the conflict of intense ambivalence towards the deceased that thwarts the detachment

process. Rather than engaging in the work of mourning, the bereaved individual retains an unconscious identification with the deceased and, consequently, redirects negative feelings about the lost love object inwardly in the form of depressive self-reproaches or guilt. Freud's (1917/1957) 'grief work' perspective has historically dominated the bereavement literature over much of the past century.

Parkes (1970, 1972) outlines four phases of mourning. Phase I is the period of numbness that occurs close to the time after the loss. This numbness, which is experienced by most bereaved individuals, assists in disregarding the actuality of the loss at least for a brief duration of time. Then follows Phase II, the phase of yearning and protest, in which the griever yearns for the lost person to return, and there is a tendency to deny the permanence of the loss. Feelings of anger and guilt play a significant role during this phase. Phase III is the phase of disorganization and despair, where the mourner finds it strenuous to function in their environment. Ultimately, the bereaved individual is able to enter Phase IV, the phase of reorganized behaviour, where life is pulled back together, emotions are reinvested back into living life fully, and not only are plans made for the future, but there is acknowledgement that there is a future. Parkes (1988) maintains that during the phases of mourning, both cognitive and emotional changes occur, and the bereaved may develop new worldviews as a response to his/her experience of the loss, thereby reshaping his/her internal world.

Bowlby (1980), whose work overlapped with that of Parkes, reinforced the notion of phases, postulating that the mourner must pass through a series of phases before mourning is resolved. Moreover, there are overlaps between the various phases and they are seldom distinct. Other bereavement theorists such as Gozder (1985), Zisook and DeVaul (1985), Horowitz (1990) and Sanders (1999) have pointed at similar phases to those proposed by Parkes.

According to Worden (1991), the term 'phases' implies passivity, inferring that the mourner has something they must passively go through over time. Others have conceptualised mourning as a more active process entailing a series of tasks.

2.2.2 *Tasks*

The use of the term 'task' intimates that the grieving process is an active process that the griever needs to engage with after a significant loss is experienced. The conception of tasks is to some extent aligned with Freud's (1917/1957) idea of 'grief work.' Attig (1996) posits that, unlike bereavement, over which we have no control, grief involves choices in coping. Worden (2003) asserts that mourning is not a state but a process, therefore the tasks require effort.

From this perspective, Worden (1991, 2003) discusses, in detail, four tasks of mourning that must be accomplished for equilibrium to be re-established and for the process of mourning to be complete. He compares the four tasks of mourning to child growth and development, in that just as there are specific developmental tasks (physical, social and emotional) that a child needs to achieve in order to grow (for example, learning to crawl before walking), uncompleted grief tasks can impair further growth and development. Although the tasks do not follow a specific order, there is some ordering suggested in the descriptions. A particular task at a lower level needs to be completed before a task at a higher level can be attained. For example, the emotional impact of the loss cannot be worked with until the bereaved individual has accepted the reality of the loss.

For Worden (1991, 2003), the first task is to acknowledge and accept the reality of the loss. When a loved one dies, even if the death is anticipated, there is always a sense that it has not really occurred and it can be tempting to deny the reality of the loss. Thus, the first basic task of grieving is to acknowledge fully and openly that the person is dead and to come to the realization that the person will never return. Part of acceptance of reality is to understand that reunion is not possible, at least in this lifetime. Parkes (1972) and Bowlby (1969) have written at length on searching behaviour, which directly relates to the achievement of this task. Many people who have sustained a loss may find themselves calling out for the lost person or misidentifying others who remind them of the deceased, ultimately having to bring themselves back to the reality that their loved one is really dead.

Dorpat (1973) asserts that through the psychological defense mechanism of denial, some people refuse to accept and believe that the death is real, hence getting stuck at this first task in the mourning process. Denial most often involves the facts of the loss, the meaning of the loss, or the irreversibility of the loss. According to Gardiner and Pritchard (1977), denying the facts of the loss falls on a continuum from a slight distortion to a full-blown delusion. An example of denial through delusion involves the bereaved keeping the deceased's body in the home for a number of days before informing anyone of the death. Gorer (1965) claims it is more likely, though, that the bereaved would hold on to possessions of the deceased's in a mummified condition ready for use when he/she returns. Similarly, parents who lose a child, regardless of the type of loss, often preserve the child's room as it was prior to the death. This is normal and not uncommon in the short term, however could develop into denial if it continues for an extended period of time (Worden, 2003).

Worden (2003) writes that denying the meaning of the loss manifests through minimization and selective forgetting. With minimization, the loss is viewed as being less significant than what it actually is. Statements such as, "*he was not a good father,*" "*we were not close,*" or "*I do not miss him*" illustrate this (p. 28). In addition, all kinds of reminders, personal items and artifacts of the deceased are quickly removed, which is the opposite of mummification. Minimization usually stems from a conflicted relationship with the deceased. Selected forgetting, on the other hand, involves entirely blocking the deceased person from one's mind, including a literal visual image of that person.

Another way in which people protect themselves from reality, and in turn obstruct the completion of the first task, is by denying the irreversibility of death. With this kind of denial, the bereaved individual needs to acknowledge and realize that the loved one is dead and not returning. Yet, coming to an intellectual as well as emotional acceptance of the reality of a loss or the finality of death takes time- sometimes even months. Belief and disbelief are intermittent while grappling with this basic task (Worden, 2003).

The second task, according to Worden (1991, 2003), is working through the emotional turmoil or pain of grief. The intense pain of grief manifests physically, emotionally and behaviourally. *"If it is necessary for the bereaved person to go through the pain of grief in order to get the grief work done, then anything that continually allows the person to avoid or suppress this pain can be expected to prolong the course of mourning"* (Parkes, 1972, p. 173). For a long time after the death, there may be no strength for the most ordinary of daily tasks (Sanders, 1999; Staudacher, 1987).

Importantly, various mediators of mourning account for and explain not only varying grief reactions that emerge, but also the mourner's ability to confront and deal with very painful feelings triggered during this second task. The mediating factors include who the deceased was, the nature of the attachment relationship to the deceased (close, ambivalent, conflicted, narcissistic, and dependent), the mode of death (sudden or expected, violent/traumatic, preventable, ambiguous and stigmatized), historical antecedents of the mourner (prior mental health history and how previous losses were grieved), personality variables of the mourner (age and gender, coping style, attachment style, cognitive style, ego strength, and assumptive world), social variables (support availability, support satisfaction, social role involvement, experience of multiple losses, and religious resources) and concurrent stresses (Cook & Dworkin, 1992; Horowitz; 1990; Worden, 2003).

The pain of grief includes common feelings such as sadness, dysphoria, anxiety, anger, guilt, frustration, withdrawal, despair and loneliness (Becvar, 2001; Deits, 2000; Staudacher, 1987; Worden, 2003). An inability on the part of the mourner to work with, and work through these complex and complicated feelings could potentially set up a complicated bereavement (Bowlby, 1980).

The third task is adjusting to the environment where the deceased is missing or absent. Worden (2003) highlights three domains of adjustment that the mourner needs to make after losing a loved one to death: external adjustments, internal adjustments and spiritual adjustments.

External adjustment focuses on how the death affects the bereaved's day-to-day functioning in the world. Adjusting to a new environment varies, depending on the nature of the relationship with the deceased and the different roles the deceased fulfilled. The survivor is not usually aware of all the roles played by the deceased until some time after the loss occurs, when new skills have to be learnt and roles assumed that the deceased formerly performed. The coping strategy of redefining the loss so that it can benefit the survivor, more often than not, forms part of the accomplishment of this task.

Internal adjustment accounts for the way in which the death of a loved one affects the mourner's sense of self. Sense of self encompasses self-definition, self-efficacy and self-esteem. Zaiger (1985) posits that for those women who define their identity through relationships and taking care of others, bereavement means not only the loss of a significant other but also the sense of a loss of self. In addition, a person's sense of self-efficacy, that is, the degree to which the person feels they have some control over what happens to them in their lives, can lead to intense regression when the bereaved perceive themselves as helpless, incapable and inadequate (Horowitz, Wilner, Marmar & Krupnick, 1980). Attempts to carry out the deceased's roles may fail, leading to a further sense of lowered self-esteem. When this occurs, personal efficacy is challenged (Goalder, 1985). Attig (1996) emphasizes that the internal task for the mourner in adjusting to the environment is to address the question, 'Who am I now?'

Spiritual adjustment describes how a death shatters the griever's beliefs, values and assumptive world. Loss, through death, challenges one's fundamental life values and philosophical beliefs, thus it is not peculiar for the bereaved to feel they have lost direction in life. Meaning in the loss is searched for in order to make sense of the traumatic event, and as a way of reclaiming a sense of control over one's life (Neimeyer, 1998). Janoff-Bulman (1992) emphasizes three fundamental assumptions that are often threatened after a significant loss: that the world is a benevolent place, that the world makes sense, and that the person him/herself is worthy.

The arresting of Task III stems from not adapting to the loss by not developing the skills needed to cope, by withdrawing from the world and not facing up to environmental requirements or by not moving forward with a reassessed sense of oneself (Worden, 2003).

The fourth task is emotionally relocating the deceased and moving on with life. Previously Worden (1991) viewed this fourth task of mourning as withdrawing emotional energy from the deceased and reinvesting it in other relationships, which is in accordance with Freud's (1917/1957) third phase of mourning. However, recent literature demonstrates that the bereaved do not decathect from the deceased, but rather find alternate ways of continuing bonds or attachments with loved ones through memorializing- remembering the lost person (Klass, 1999; Klass, Silverman & Nickman, 1996). Therefore, the fourth task of mourning is to *"find a place for the deceased that will enable the mourner to be connected with the deceased but in a way that will not preclude him or her from going on with life"* (Worden, 2003, p. 35).

The four tasks of mourning mentioned above are revisited and reworked intermittently over time and various tasks can also be worked on simultaneously. Grieving is thus a fluid process (Worden, 2003).

The section that follows illustrates how the mourning process can be understood in terms of several stages.

2.2.3 Stages

Kubler-Ross (1969, 1974, 2005) conceives of the grieving process as composing of five stages: denial, anger, bargaining, depression and acceptance. These stages apply not only to the process of accepting one's own death, but also to accepting other difficult and catastrophic life experiences, such as losing a loved one. The different stages are emotional responses to loss that most mourners go through and *"are a part of the framework that makes up our learning to live with the one we lost"* (Kubler-Ross, 2005, p. 7). Kubler-Ross (1969, 2005) states that not everyone will go through all of these

stages, and that they do not follow a prescribed, linear order. Each stage will be discussed separately below.

The first stage is denial. When a person is in denial, he or she may initially respond to the loss of a loved one by being *“paralyzed with shock”* or *“blanketed with numbness”* (Kubler-Ross, 2005, p. 8). The denial is not denial of the actual death and is considered to be more symbolic than literal, even though the person might say: ‘I cannot believe that he is dead.’ These kinds of comments are, at first, merely protecting the psyche from unbearable pain. Denial and shock help the bereaved cope, and make survival possible. *“Denial helps us to pace our feelings of grief. There is a grace in denial. It is nature’s way of letting in only as much as we can handle”* (Kubler-Ross, 2005, p. 10). Allowing in all the feelings associated with loss at once at this stage would be too emotionally overwhelming. As denial begins to fade, it is slowly replaced with the reality of the loss and all the feelings that were being denied begin to come forth.

Stage two is anger. The anger that emerges at this particular stage does not have to be valid or logical and manifests itself in a myriad of ways: anger at friends, the doctors, family, oneself, the loved one who died, and at God. *“There you sit, alone with your anger, wondering how to reconcile your spirituality and your religion with this loss and anger”* (Kubler-Ross, 2005, p. 13). Anger and rage at God is very common, as the mourner questions God and his role when a significant loss occurs. One’s anger needs to be acknowledged, honoured and explored, as the pain of loss lies underneath it. Feelings of anger are *“a natural reaction to the unfairness of loss”* (Kubler-Ross, 2005, p. 16).

The third stage is bargaining. After a death, bargaining may take the form of a provisional truce. The mourner gets caught up in ‘If only...’ and ‘What if...’ statements in an attempt to return life to what it was. *“Guilt is often bargaining’s companion. The ‘if onlys’ cause us to find fault with ourselves and what we ‘think’ we could have done differently”* (Kubler-Ross, 2005, p. 17). Bargaining can be an important reprieve from pain, as one can find momentary relief in it. The stage of bargaining gives one’s psyche

the time it may need to adjust to the loss, allowing one temporarily to believe that one can restore order to the chaos.

Stage four is depression. Kubler-Ross (1969, 2005) clearly states that depression is not a sign of mental illness but rather a normal and appropriate response to a significant loss. *"To not experience depression after a loved one dies would be unusual"* (Kubler-Ross, 2005, p. 21). At this stage, the mourner withdraws from life, as it feels futile and empty. Kubler-Ross (2005) explains that depression protects the griever by shutting down the nervous system so that adaptation to the loss can occur. The mourner needs to experience the sorrow and sadness that naturally follows after the loss of a loved one.

The fifth and final stage is acceptance. *"This stage is about accepting the reality that our loved one is physically gone and recognizing that this new reality is the permanent reality"* (Kubler-Ross, 2005, pp. 24-25). It is the new norm, which the bereaved learns to live with. With acceptance comes healing, and healing includes remembering, recollecting and reorganizing. The mourner learns to readjust to the environment, reorganize roles and reintegrate- *"trying to put back the pieces that have been ripped away"* (Kubler-Ross, 2005, p. 25). Acceptance involves remaining connected to the deceased by remembering them and commemorating the loss, in conjunction with reinvesting energy into life and new meaningful relationships.

2.3 Complicated Bereavement

Whether the mourning process is understood in terms of phases, tasks or stages, the literature suggests that it is crucial that death is confronted and processed emotionally (Barlow & Durand, 1999). *"If the bereavement process is avoided or truncated, the risk to the survivor's ability to manage the demands of living are increased"* (Rubin, 1984, p. 340). Complicated mourning has been referred to by many different names such as pathological grief, unresolved grief, abnormal grief, and complicated bereavement (Worden, 1991). These various names will be used interchangeably or as synonymous expressions when discussing the term complicated mourning. Pathological grief is often a highly intense and out-of-control experience of the kind of ideas and feelings normally

found during mourning (Raphael, 1983). One of the most common definitions of complicated bereavement is mourning that is either delayed or prolonged (Zisook & DeVaul, 1985), and *“complicated grief disorders may include symptoms such as intrusive images, severe pangs of emotion, denial of implications of the loss to the self, and neglect of necessary adaptive activities at work or at home”* (Horowitz, Siegel, Holen, Bonanno, Milbrath & Stinson, 1997, p. 904). However, the literature acknowledges that there is a continuous relationship between normal and abnormal grief reactions, between the complicated and uncomplicated, as the symptoms are similar; thus pathology is rather defined by the intensity and duration of a reaction (Hartz, 1986; Horowitz et al, 1980; Worden, 2003).

Up until the 1980s, it was assumed that the grieving process was time-limited (Peretz, 1970) with the standard being two weeks during which the mourner experienced shock (Becvar, 2001). These first two weeks were then followed by two months of intense grieving. Finally, after two years the grief decreased and the bereaved individual recovered, returning to full, normal functioning. By the end of this two-year period the grieving process was to have concluded (Becvar, 2001).

Complicated or abnormal grief reactions manifest in various ways. This includes chronic grief reactions (also called prolonged or interminable grief), delayed grief reactions (also called inhibited, suppressed or postponed grief), exaggerated grief reactions, and masked grief reactions (Worden, 1991, 2003). Each grief reaction is discussed briefly.

Chronic grief reactions are excessive in duration and occur when bereaved individuals cannot speak of the loss without intense overwhelming pain. For years after the loss, unrelated events still trigger intense grief responses, themes of loss often arise in everyday conversations, and the bereaved has not resumed normal everyday functioning. The bereaved person is very much aware that he or she is not working through the period of mourning (Worden, 1991).

Delayed grief reactions take place when emotional reactions at the time of the loss are not sufficiently expressed. Thus, the symptoms of grief are experienced over a subsequent loss at a future date. Geller (1985) offers an example of a woman who lost several of her children in an accident. She was pregnant at the time and was advised not to get too emotional, as intense feelings could jeopardize her pregnancy. She heeded this advice, only to have intense grief appear when her eldest child left home. Multiple losses can also cause grieving to be postponed due to the magnitude of the loss, commonly referred to by Kastenbaum (1986) as bereavement overload.

Exaggerated grief responses transpire when the bereaved person feels overwhelmed by the intensity of the normal grieving process and as a result may resort to maladaptive behaviours. The person is aware that the excessive and disabling symptoms and behaviours they are experiencing are related to the loss. Exaggerated grief reactions include psychiatric disorders that develop following a loss, which often receive a DSM diagnosis such as clinical depression, anxiety disorders (social phobia and agoraphobia), eating disorders, substance abuse, Post-Traumatic Stress Disorder (PTSD), and mania (Cook & Dworkin, 1992; Worden, 2003).

Lastly, masked grief reactions incorporate grief-related facsimile illnesses whereby the bereaved individual experiences the same physical or medical symptoms of the deceased's illness or they may develop some other kind of unrelated psychosomatic complaint. Furthermore, there is greater focus on the bereaved individual's physical well-being rather than dealing with the emotional aspect or pain of the loss (Zisook & DeVaul, 1985). Non-affective symptoms are developed, which are seen as affective equivalents of grief. The bereaved person is unable to recognize that the physical symptoms are connected to the loss (Worden, 2003).

More often than not, mediating factors (circumstantial factors, relational factors, historical factors, personality variables, and social factors) highlighted earlier under Task II of the four tasks of mourning, explain why some bereaved individuals fail to grieve,

potentially developing a complicated grief reaction (Becvar, 2001; Cook & Dworkin, 1992; Deits, 2000; Staudacher, 1987; Worden, 1991, 2003).

2.4 *Evaluation of Models of Mourning*

Throughout the grieving process, the basic goal was that of detaching from emotional ties to the deceased in order to be able to form new relationships with those who were still living (Bowlby, 1980). Furthermore, should the grief not be resolved within the designated appropriate amount of time, that is, two years, mourning was considered to be maladaptive (Raphael, 1983).

However, during the 1980s, the duration of the grieving process was challenged and viewed differently. Hartz (1986) stresses that grieving is a non-linear process that may occur cyclically, with no specific end point. It can therefore involve alternating periods of intensification and subsiding of symptoms and these may return for years after the loss (Herman, 1992). While the grieving process is a natural and normal emotive response to endings, it is highly personal and individualistic (Cavanaugh & Blanchard-Fields, 2002; Kubler-Ross, 2005). Thus, according to Rynearson (1987), grieving behaviour is not always predictable. Volkan (1985) asserts that mourning ends when the mourner no longer has a need to reactivate the representation of the dead with exaggerated intensity in the course of daily living. *“One benchmark of a completed grief reaction is when the person is able to think of the deceased without pain. There is always a sense of sadness...but it is a different kind of sadness- it lacks the wrenching quality it previously had... mourning is finished when a person can reinvest his or her emotions into life and in living”* (Worden, 2003, p. 46).

Over the past century, a considerable body of literature has been generated to describe the phenomenology of the grieving process. Much of this literature stems from the psychoanalytic perspective of Freud (1917/1957), where recovery from a significant loss requires a period of ‘grief work’ in which the ultimate aim is the severing of the attachment bond to the non-existent love object (Becvar, 2001; Bonanno, 2004; Bonanno & Kaltman, 1999; M. Stroebe & W. Stroebe, 1991). As researchers began to devote more

attention to the bereavement process, however, it became apparent that despite the close agreement with which mental health professionals upheld the grief work perspective there was a lack of empirical support for this view (Wortman & Silver, 1989). During the 1980s several empirical studies not only challenged fundamental assumptions regarding Freud's classical model of the grieving process and recovery (Demi & Miles, 1987; Fish, 1986; Fulton, 1987), but also suggested that it may be harmful for bereaved individuals to adopt such an approach (Bonanno & Kaltman, 1999). Those critiques that relate specifically to the process of meaning-making after parental bereavement will be discussed.

First, complete detachment or decathexis from the deceased came to be understood as neither desirable nor possible. Bereavement theorists began to realise that the bereaved are able to maintain a simultaneous attachment to both the living and to the one who has died, and still function effectively in day-to-day living (Becvar, 2001). Silverman and Klass (1996) suggest that *"interdependence is sustained even in the absence of one of the parties...the bereaved remain involved and connected to the deceased, and actively construct an inner representation of the deceased that is part of the normal grieving process"* (p. 16). Fairbairn (1952) and Kernberg (1976) define inner representation as the part of the self actualized in the bond with the person, characterizations and thematic memories of the person, and the emotional states connected with the characterizations and memories. For example, bereaved parents may make meaning in their own lives through continuing bonds or connections with the deceased via their inner representation of the child. Thus, according to Neimeyer (2001), the resolution of parental grief is not a severing of the bond with the dead child but rather may entail an integration of the child into the parent's life in a different way than when the child was alive.

Moreover, Schwartzberg and Halgin (1991) also propose a meaning-making strategy that bereaved parent's employ as a way of keeping the deceased person 'alive,' and in turn maintaining a positive relationship and connection with the deceased. This is achieved through *"internalizing the deceased person"* (p. 243), which is similar to the notion of inner representation, discussed above. The bereaved may keep a lost loved one alive

internally by continuing to hear the voice of the deceased giving guidance, support, approval or even criticism. Some use the memory of their lost loved one to encourage them or spur them on to achievement, in a sense dedicating their efforts or accomplishments as a tribute. According to Shapiro (1996), *“grief is resolved through the creation of a loving, growing relationship with the dead that recognises the new psychological or spiritual dimensions of the relationship”* (p. 552).

A second critique is that mourning is not a private, intrapsychic process but is social and relational. Isolated mourning does not recognise the important and integral role of relationships and the social milieu in the grieving process. Human psychological life is profoundly relational and intersubjectively based, in which meaningful connections are formed with others that may facilitate or impede recovery from bereavement (Neimeyer, 2001; Stolorow & Atwood, 1992). In a study conducted by Wheeler (2001), the most cited area of meaning-making for bereaved parents was meaningful contact with people: surviving children, spouse, grandchildren, children born since the death, family, friends and other bereaved parents. The second largest area of meaning-making was placed in the context of helping others: work or career, volunteer work connected with the child or the child's death, helping other bereaved parents, educating others about grief and helping people in general. This new perspective links with the concept of inner representation in that *“no matter how withdrawn into grief a person appears to be, he or she is struggling to maintain relatedness, whether to the internal representation of the dead person or to the social surround”* (Neimeyer, 2001, p. 25).

Third, the complexity and uniqueness of each mourning experience is not recognised in traditional models of mourning. The traditional Freudian view that the process of mourning has normal, standardized characteristics (Neimeyer, 2001) ignores highly personal and cultural reactions to loss (Cavanaugh & Blanchard-Fields, 2002; James & Gilliland, 2001). Standard theories of mourning tend to be Western and Eurocentric, with little consideration of cultural variations in the bereavement process (Stroebe et al., 1992). Bereavement may take many forms and the degree to which it is adaptive or maladaptive can only be determined on an individual basis (Becvar, 2001), not by

successful progression through a specific sequence of phases (Neimeyer, 2001). Parental bereavement, in particular, involves a crisis of meaning, and the search for meaning is personal yet central to the process of readjustment after the death of a child (Wheeler, 2001). Therefore acknowledgement needs to be given to the tremendous challenge to belief systems, to daily life and to the self-concept that the loss of someone close represents (Becvar, 2001). Up until recently, searching for meaning in a child's death has not been accounted for by existing phase-based models of grief (Braun & Berg, 1994).

This shift in perspective represented by the more recent models of bereavement (see Worden, 2003) demonstrates that, rather than pathologizing an individual's grief process, each person's reactions need to be understood in the context of his or her worldview and unique situation (Becvar, 2001). The goal becomes one of facilitating adaptation instead of overcoming a major loss (Bernstein, 1997).

Lastly, from a trauma perspective, the death of a loved one is considered to fall in the larger category of possible traumatic experiences a person might endure (Bonanno & Kaltman, 1999). In addition, grief reactions often involve more than signs and symptoms of major depressive disorder (Horowitz et al., 1997). Yet, the models of mourning-phases, tasks and stages -seem mainly to highlight depressive symptomatology as a likely emotional response to a significant loss. Thus, present development has been the acknowledgment that grief includes post-traumatic stress (Figley et al., 1997; Zoellner & Maerckner, 2006). Child death is considered to be a traumatic life event (Rando, 1997) and mental health professionals working with bereaved parents need to assess symptoms of post-traumatic stress and take into account the prospect of trauma work before dealing with post-loss adjustment (Herman, 1992; Rando, 1993). If the trauma itself is not worked with and worked through, the bereaved individual may run the risk of developing a pathological grief response (Rando, 1997).

2.5 *Anticipated Bereavement*

Staudacher (1987) describes common reactions that may occur amongst parents when childhood death, due to a malignant disease, is anticipated. The first reaction is non-

acceptance of the fatal prognosis, instead either assimilating the prognosis gradually, or denying it until the child is in the last stages of dying. The second reaction includes fantasizing, unconsciously or unconsciously, about the child experiencing a miraculous recovery. Another reaction involves parents trying their own various healing techniques such as visualization, providing an alternate diet to the child, changing religious affiliations, engaging in certain activities that should bring 'good luck,' or bargaining with an omnipotent power, for example God. The final reaction entails explaining the child's illness as an indirect punishment for some past behaviour for which parents might feel ashamed or guilty.

Since the grief associated with losing a child (young or old) to a chronic illness, such as cancer, is anticipated, the grieving process may begin prior to the actual loss (Humphrey & Zimpfer, 1996). The expectancy of the death supposedly buffers the impact of the loss when it happens (Cavanaugh & Blanchard-Fields, 2002), and facilitates more rapid recovery of effective functioning (Glick, Weiss & Parkes, 1974). Worden (2003, p. 140) maintains that *"the time preceding a death can be used very effectively and can have an important impact on subsequent grief if the survivor is encouraged to take care of unfinished emotional business,"* as this leaves little room for later regrets. An anticipated death often is less mysterious, whereas when the death is unexpected the mourner is left with many more unanswered questions (Attig, 1996). Becvar (2001) states that in all cases of anticipated grief, *"...the goal is to create a context that enables the dying person to live as fully as possible while facilitating his or her ability to die well"* (p. 69). Staudacher (1987) understands the process of anticipated bereavement in the following way. She postulates that the grieving that occurs prior to the loss stems from knowing that one's child is going to die, whereas the grief that surfaces post-loss stems from the actual death.

Nonetheless, anticipating the death of a loved one creates distress in itself (Attig, 1996; Norris & Murrell, 1987). For example, assuming the role of caretaker for the person who is ill, witnessing a loved one suffer from an extended illness (Becvar, 2001), which more often than not, has a progressively deteriorating course (Taylor, 1983), enduring a long

series of intensive medical treatments (Worden, 2003), uncertainty of outcome, economic burdens, discussing the impending death with a sick loved one, and/or preparing advance funeral arrangements (Koocher, 1986). According to studies conducted by Parkes (1975), parents who have some advance warning of a pending death function better when assessed at 13 months post-death than parents who do not have this advance warning. However, not all studies draw the same conclusions. For example, Hogan, Morse & Tason (1996) found that anticipatory grief did not ameliorate or foreshorten the bereavement process.

2.6 Empirical Research on Parental Bereavement

A great deal of research on grief has centered on the experiences of loss of a spouse (Schuchter, 1986), and on gender differences in coping with, and adjusting to, the loss of a spouse (Schut, Stroebe & van den Bout, 1997; M. Stroebe, W. Stroebe & Schut, 2001). Comparatively few studies have focused on the experiences of bereaved parents, despite the fact that child death has been identified as the most grievous of losses (Miles, 1985; Sanders, 1980; Videka-Sherman, 1982).

The literature on parental bereavement has concentrated primarily on the psychological and social aspects of coping with the death of a child to cancer (Koocher, 1986), as well as on parents' reactions to their child's death. This includes emotional and psychological responses such as anxiety (Clerici, Ferrari, Massimino, Luksch, Cefalo, Terenziani, Polastri, Meazza, Podda & Fossati-Bellani, 2006; Osterweis, Solomon & Green, 1984), helplessness (Dean, McClement, Bond, Daeninck & Nelson, 2005), depression (Kreichbergs, 2004; Moore, Gilliss & Martinson, 1988), guilt (Barr, 2004; Miles & Demi, 1984), anger and hostility (Cook, 1983), isolation (Morrow, Hoagland & Carnrike, 1981), and despair and hopelessness (Staudacher, 1987), as well as physical symptoms and somatic complaints resulting from bereavement (Birenbaum, Stewart & Philips, 1994).

Bereavement affects the way in which parents relate to each other, the relationships that they have with the living children, with friends, at work and with others. Enduring grief along the life cycle is an un-patterned process, with emotional and cognitive ups and

downs, involving a continuous search for meaning to life (Malkinson & Bar-Tur, 2004). Three main phases in the bereavement process have been identified; the immediate acute phase (young grief), grief through the years until aging (mature grief) and bereavement in old age (aging grief) (Malkinson & Bar-Tur, 2004). Furthermore, bereaved parents identified the need for more supportive contact from hospital staff during the palliative phase and following the death of a child, early provision of information on how to practically and emotionally prepare for the death of their child, contact with other bereaved parents and formal grief support for siblings (Clerici, Ferrari, Massimino et al., 2006; Dean et al., 2005; Monterosso et al., 2006).

Incorporated in this area of research are mother's experiences of living with children with cancer, parental communication and children's behaviour following a childhood cancer diagnosis, and the long-term effects of parental bereavement on surviving children. A cancer diagnosis brings with it a set of new responsibilities and role expectations, including an obligation of 'proximity' - being physically close to their child at all times to provide 'comfort' and 'keep-watch.' For mothers, caring evokes an intense emotional interdependence with their sick child, and involves a range of technical tasks and emotional work, including acting as 'brokers' of information for their child and managing their co-operation regarding treatment. This often results in severe role strain by compromising their ability to function in other roles, including their role as mother of their other children (Young, Dixon-Woods, Findlay & Heney, 2002). The importance of supporting mothers in ways that enable them to fulfill their role as parents of a child in crisis is emphasized, which involves family social support (McMenamy & Perrin, 2003).

Moreover, many parents find decisions about what to tell their child with cancer difficult. Open and honest communication about the illness is generally considered the best approach, and older children were given more information. Most children showed behavioural and mood difficulties after diagnosis. In addition, parents' perceptions of childhood cancer affect the way they communicate with their child (Clarke, Davies, Jenney, Glaser & Eiser, 2005). In the aftermath, bereaved parents struggle with their sense of competence, mourn the lost parent-child bond and feel a loss of parental hopes

sense of competence, mourn the lost parent-child bond and feel a loss of parental hopes for the future. A child's death shapes surviving parent-child relationships, as parents mediate the loss experience for their other children, become more protective, and increase their parental efforts (Malkinson & Bar-Tur, 2004).

Research has also explored potential risk factors for complicated bereavement. Parents who have lost a child have a higher overall relative risk of a first psychiatric hospitalization for any disorder. More specifically, bereaved mothers have a higher relative risk than bereaved fathers of being hospitalized for any psychiatric disorder during the first year after the death of the child and this risk remains significantly elevated five years or more after the death (Li et al., 2005). Other factors, such as routine psychosocial screening, especially for families undergoing stem cell transplant, may contribute usefully to a proactive model of palliative care in identifying parents at risk for complicated bereavement outcomes (Drew, Goodenough, Maurice, Foreman & Willis, 2005). Another study conducted a national survey in order to develop a Bereavement Risk Questionnaire rating possible factors for assessing complicated bereavement. Perceived lack of social support and poor coping skills were rated as the highest risk factors. The researchers concluded that it is possible to assess bereavement risk in caregivers of seriously ill patients, prior to the death of the patient, which would allow palliative care teams to allocate resources and services to those at greatest risk for complicated bereavement (Ellifritt, Nelson & Walsh, 2003).

The limited research literature on parental bereavement also includes some case studies. A collective case study of Mexican American families identified eight common themes, reflecting the ways in which family members maintained their bond to the deceased: dreams, storytelling, keepsakes (cherished objects used by the deceased), sense of presence of the deceased, faith-based connections (spiritual and religious beliefs), proximity connections (place of burial), ongoing rituals, and pictorial remembrances (Doran & Hansen, 2006). Other case studies have explored experiences of pediatric hospice care including the decision to terminate aggressive treatments, the anticipation of

death, and the grief and bereavement of family members of different ages (Bosticco & Thompson, 2005; Lambrinidou, 2000).

Many studies have also been conducted on gender differences in parents following bereavement (Bohannon, 1990; Littlefield & Rushton, 1986). Research illustrates that most bereaved parents rely predominantly on their partner or spouse for sustained support and understanding. Over time, partners often experience increased difficulties in supporting each other due to gender differences in grief and coping, strained communication and characteristic patterns of misunderstandings (Wing, Burge-Callaway, Clance & Armistead, 2001).

Men and women express grief differently (Schwab, 1996). Doka and Davidson (1998) suggest that men and women are more alike than they are different; yet it is easy to cite gender as the reason for observed variance in grieving patterns between them. Thus, Doka and Davidson (1998) suggest that it would perhaps be more useful to focus on the differences between the concepts of 'masculine' and 'feminine' grief because all males are not masculine grievers, and all women are not feminine grievers. Feminine grief is characterized by intensely expressing a wide range of feelings, sharing openly with others and receiving one-on-one counselling, as well as group psychotherapy. This expression of grief is generally associated with women. The notion of masculine grief originated from a desire to validate men's expression of grief, which is often inexpressive, muted or moderated, and is incorrectly equated with someone who is unable to respond and adapt to loss.

In approximately the last decade, empirical research has also investigated the role of religion in adjusting to the loss of a child, the relationship between religious coping and psychological distress, and the long-term effect of institutional religion on bereaved people's religious and spiritual beliefs. Results from these studies indicate that religion (religious participation and religious importance) is positively related to cognitive processing and finding meaning in the death, and is associated with greater well-being and less psychological distress post-loss (Cardella & Friedlander, 2004; McIntosh, Silver

& Wortman, 1993). However, older bereaved people are disappointed with the support they receive from institutional religion (Coleman, Ivani-Chalian & Robinson, 2004).

More recently, empirical research has centered on exploring continuing bonds with the deceased (Russac, Steighner & Canto, 2002), and the link between death-specific religious beliefs (belief in an afterlife) and continued attachment (Benore & Park, 2004). This research has found that death-specific beliefs (belief in an afterlife) and continued attachment are vital determinants of adjustment to, and coping with, bereavement.

Several methodological issues arise from the bereavement research that are worthy of discussion.

The first issue is that bereavement researchers have used both cross-sectional and longitudinal designs, and an overwhelming majority of the studies are retrospective. Cross-sectional designs do not allow for the examination of predictor variables, but have proved to be valuable in discovering the phenomenological features of grieving at various points in the bereavement process (Bonnano & Kaltman, 1999). On the other hand, longitudinal designs are limited by the minimal amount of experimental control they afford, but do allow for potential assessment of predictor variables. Longitudinal designs also allow researchers to concentrate on a range of different empirical questions from the same data set (Bonnano & Kaltman, 1999), and can be advantageous as multidimensional assessments are conducted (Zisook & Shuchter, 1993), however the likelihood of overreporting similar results is increased (Bonanno & Kaltman, 1999). Many of the retrospective studies are synopses of clinical experiences or of a relatively little number of case studies. Although the results are often of limited generalizability, such studies add depth and richness to the clinical literature (Koocher, 1986).

A second concern is that the studies on bereavement vary in their sampling methods, suggesting the possibility for selection biases. Locating a sample and gaining co-operation to perform research on a topic as sensitive as bereavement can be a challenge. Bereaved individuals may have not much reason to trust or share their private pain with

Although some of the empirical research conducted on parental bereavement has employed quantitative instruments such as questionnaires, inventories, surveys and rating scales, an overwhelming majority of the studies have used semi-structured interviews as a way of gaining rich, meaningful and detailed personal accounts of grieving experiences.

2.7 *Meaning-Making*

As noted previously, the death of a child has been conceptualised as a crisis of meaning for the bereaved parent (Braun & Berg, 1994; Miles & Crandall, 1983; Wheeler, 2001). Meaning-making resulting from this crisis is considered a significant part of the adjustment and recovery process (Frankl, 1986; Janoff-Bulman, 1992; Parkes & Weiss, 1983; Rando, 1986; Taylor, 1983). Although theorists concur on the psychological importance of meaning-making, conceptualizations of what constitutes meaning vary and definitions of meaning-making have been too broad to facilitate a clear understanding of the psychological processes involved. Meaning-making has encompassed various concepts such as attributional concerns, existential confrontation, purpose, making sense, finding meaning, account-making, meaning reconstruction, searching for meaning, and explaining the event (Davis et al., 1998; Harvey, Orbuch, Chwalisz & Garwood, 1991; Janoff-Bulman, 1992; Moos & Schaefer, 1986).

In spite of the complexity and diversity of the concept, two major components of meaning-making can be extrapolated from the trauma literature dealing with traumatic life events: the search for cognitive mastery (meaning-as-comprehensibility) and the search for renewed purpose (meaning-as-significance) (Janoff-Bulman, 1992; Tedeschi & Calhaun, 1995).

Cognitive mastery (meaning-as-comprehensibility) refers to the extent to which the event makes sense or fits with one's conception of how the world is assumed to work. People tend to assume that negative events are not distributed randomly, that people get what they deserve and that justice will prevail (Davis et al., 1998; Janoff-Bulman, 1992). One's social environment is therefore perceived as predictable, ordered and benign. Loss and trauma have the potential to threaten both one's sense of meaning in life, and the

tend to assume that negative events are not distributed randomly, that people get what they deserve and that justice will prevail (Davis et al., 1998; Janoff-Bulman, 1992). One's social environment is therefore perceived as predictable, ordered and benign. Loss and trauma have the potential to threaten both one's sense of meaning in life, and the assumptions one holds about the comprehensibility and meaningfulness of events (Janoff-Bulman, 1992).

After a bereavement, the process of meaning-making involves trying to understand and make sense of the death (Janoff-Bulman, 1992). *"Psychologically, the shattering of fundamental assumptions produces a state of both loss and disintegration; the known, comforting old assumptive world is gone, and a new one must be considered"* (Janoff-Bulman, 1992, p. 71). The shattering of prior unquestioned assumptions can present a massive challenge (Rowe, 1983), as the bereaved person undergoes a process of relearning the world without the deceased (Attig, 1996). Making sense of the event requires that fundamental questions are asked, such as, 'How did it happen?' and 'Why did it happen?' In trying to answer 'how,' bereaved individuals try to find information about the sequence of events leading up to the loss. They search for ways they, or others, could have intervened to prevent the death (Chodoff, Friedman & Hamburg, 1964). 'Why' involves philosophical and/or religious beliefs about life and death. Loss of a loved one can challenge these philosophical and/or religious beliefs and the individual's fundamental assumptions about the meaning of life and death (Simons, 1979).

Thus, bereaved parents may be uniquely vulnerable to the loss of cognitive mastery after a traumatic life event. The bereavement experience of losing a child violates previous assumptions and meanings, and is particularly difficult to resolve and make meaning of, as the loss of a child can be distinguished from other traumatic losses in several ways.

The parent-child relationship has been understood as containing distinct dynamics. The process of grieving for one's child necessitates that the parent deal not only with the loss of the child, but also a loss of part of the self; part of one's physical body (Kalish, 1981). In Western culture, a child possesses several meanings for a parent, as parents naturally

invest their hopes, dreams, needs, wishes and expectations in the lives of their children, and parents are seen as an extension thereof. These investments are lost with the loss of a child (Braun & Berg, 1994). The younger one's child was at the time of death, the more expectations one had about his or her achievements, goals, and accomplishments. In this respect, the longer one's child's life expectancy was, the greater one's loss (Staudacher, 1987). With the death of a child, the meanings and purposes connected with the child are often crushed, leaving a vast emptiness that Frankl (1978) described as an existential vacuum.

A second difficulty is that there is no other social role as in the role of parent where there are so many innately assumed and socially assigned responsibilities. At the time of a child's death, parents are stripped of their identities as protectors, providers and caretakers, leaving them with an overwhelming sense of failure, due to having been unable to have exerted some control over their child's fate (Rando, 1986). Bereaved parents live with the notion that they are expected to have protected their child from pain and ultimately from death, thus feeling impotent (Sanders, 1982; Staudacher, 1987). Moreover, the death of a child is viewed as an unnatural and untimely event (Rosen, 1988). Regardless of the age of the child, the death still reverses the progression of life events for the parent as the orderliness of the universe is undermined (Gorer, 1965; Staudacher, 1987).

Experiencing the loss of an adult child can be differentiated from bereaved parents of younger children in several ways (Staudacher, 1987). Elderly parents may have to assume the role of parent to their grandchildren, which could be physically, emotionally, mentally and/or emotionally taxing at this advanced stage of life. Another aspect pertaining to the loss of an adult child is the possibility of inheriting money. This inheritance might compound existing feelings of guilt in that elderly parents "*do not want to profit from the loss*" (Staudacher, 1987, p. 111). Lastly, parents have an expectation of belief that they will die first, which holds true for any parent regardless the age of the child, however with the loss of an adult child this belief becomes more pronounced for older parents, perhaps leaving them feeling guilty for being alive.

Finally, beliefs about death and the meaning of childhood are antithetical. In Western culture death is seen as a bad and/or frightening event, sometimes even punishment (Kubler-Ross, 1969), and the death of a child is "*typically viewed as being wrong, even obscene*" (Braun & Berg, 1994, p. 125). Childhood, on the other hand, symbolizes happiness, purity and goodness (Braun & Berg, 1994). Therefore, the loss of a child creates immense confusion and challenges entrenched beliefs that death is 'bad' and childhood is 'good.'

A second construal of meaning-making is the search for renewed purpose (meaning-as-significance). This refers to the benefit, value or worth of the event for one's life (Davis et al., 1998; Kushner, 1982) and the process whereby the bereaved find reasons to continue living (Wheeler, 2001). The bereaved individual now asks the question, 'What is the value or significance of this?' Victor Frankl (1978), the foremost representative of existential psychology, believes that humans need to find a reason or purpose to live, that true fulfillment is hardly possible without a sense of purpose. In addition, the central issue for humans is not the struggle to survive but the struggle to find and experience meaning in life. He proposes that even in the most adverse of conditions, having something to live for increases the will to live in circumstances that make death seem like a possible solution. The question of finding value in traumatic experiences lies at the heart of his existential theory.

The search for renewed purpose may include many positive outcomes, such as an evaluation of important lessons learnt (involving either a newfound appreciation of life or of oneself and a greater recognition of one's vulnerability), benefits for oneself (such as an enhanced sense of personal strength as well as being a more sensitive, compassionate, patient and caring human being), long-term benefits for others (involving transforming the trauma into altruistic acts providing benefit to others), improvements in relationships with others (including a greater capacity for emotional expressiveness and self-disclosure that enhances interpersonal intimacy), and a changed philosophy in life (including a re-ordering of priorities and the development of spiritual and/or religious beliefs) (Janoff-Bulman, 1992; Neimeyer, 2001; Tedeschi & Calhoun, 1995).

culmination of grieving is not a return to the pre-grief state, but rather growth into a more confident and adaptable human being, achieving a higher level of functioning and fulfillment than existed before the trauma. Bailey and Gregg (1986) maintain that the individual who has experienced a loss and been through the mourning process may see him/herself as a survivor of a traumatic and painful experience with new resources and improved coping skills, thereby enhancing the bereaved individual's sense of self-worth. A traumatic event can therefore be conceptualised as a turning point or watershed in the survivor's life, in which previous assumptions are rebuilt, and values and priorities reconsidered (Tedeschi & Calhoun, 1995).

Janoff-Bulman and McPherson Frantz (1997) propose that successful adaptation after a significant loss involves first trying to make sense of the event (meaning-as-comprehensibility), and then finding benefit or value in the experiences for one's life (meaning-as-significance). However, the traditional literature on mourning does not consider these processes as part of the phases, tasks or stages of the bereavement process.

In conclusion, coping with parental bereavement entails a process of cognitive restructuring that could incorporate both the development of a meaningful explanatory account of the traumatic event (cognitive mastery), as well as the development of a transformative meaning that gives emphasis to the value and significance of the traumatic experience (renewed purpose). Therefore, meaning-making is different from 'grief' and 'mourning' in that the bereaved is required not only to accept the loss, but also to create meaning from it.

2.8 Empirical Research on Meaning-Making after Trauma

Researchers have historically studied typical negative reactions and psychological outcomes of life traumas, as opposed to the potentially positive impact of these events. However, recently, there have been attempts to account for perceived benefits or post-traumatic growth, collectively described as adversarial growth that would not be possible without the challenge of the traumatic event (Linley & Joseph, 2004; Tedeschi & Calhoun, 1995; Zoellner & Maercker, 2006). Importantly, the recent shift toward

without the challenge of the traumatic event (Linley & Joseph, 2004; Tedeschi & Calhoun, 1995; Zoellner & Maercker, 2006). Importantly, the recent shift toward acknowledging evidence of positive change post-trauma does not negate the existence of negative effects that may result from a traumatic experience (Morris, Shakespeare-Finch, Rieck & Newbery, 2005). There is recognition that growth and pain are inextricably linked as part of the post-trauma recovery process (Affleck & Tennen, 1996; Saakvitne, Tennen & Affleck, 1998), and that the long-term legacy of trauma involves both losses and gains (Janoff-Bulman, 1992). Linley and Joseph (2004) and Zoellner and Maerckner (2006) assert that it is the characteristics of the subjective experience of the traumatic event, for example, helplessness, life threat, and controllability, rather than the event itself, that influence adversarial growth. Interestingly, post-traumatic growth or a search for meaning is not usually a conscious goal for survivors of trauma, but rather develops as a consequence of cognitive restructuring and emotional work (Tedeschi & Calhoun, 1995).

Recent investigations have been conducted on adversarial growth in the following populations: parents of Down Syndrome children, of children with pediatric leukemia and of children who have been murdered; patients with rheumatoid arthritis, multiple sclerosis, HIV/AIDS, breast cancer, strokes, bone marrow transplantation, heart attacks, spinal cord injury and chemical dependency; and survivors of transportation accidents, mass shootings, plane crashes, house fires, tornado, rape, assault, sexual assault and sexual abuse, child sexual abuse, adult abuse, military combat, refugee experiences, and being taken hostage (see Linley & Joseph, 2004; Tedeschi & Calhoun, 2004; Zoellner & Maerckner, 2006, for a comprehensive review of this literature). Thus, the phenomenon of post-traumatic growth occurs in a wide range of people, facing an even wider array of highly stressful events.

Empirical research demonstrates that psychological growth or positive psychological changes can be organized into three main categories. The first is changes in self-perception. This entails increased perceived self-reliance and a greater sense of personal strength, and recognition and appreciation of one's vulnerability. The second category of

psychological growth is changes in interpersonal relationships. This includes valuing relationships more, increased self-disclosure and emotional expressiveness, warmer and more intimate relationships with others, increased compassion and greater sensitivity to the needs and feelings of other people, and efforts directed at improving relationships. The third aspect of post-traumatic growth is a changed philosophy of life. This includes reordered priorities, value reorganization, new appreciation for simple moments in everyday life, spiritual development and strengthened religious and/or spiritual beliefs. (see Tedeschi & Calhoun, 1995, 2004, for a comprehensive review of this literature).

Furthermore, Morris et al. (2005) recruited 219 participants from an Australian university and examined the multidimensional nature of post-traumatic growth after a specific traumatic event. The participants were instructed to answer the questionnaire in relation to a perceived traumatic event. The most frequently occurring traumatic events described by participants in this study, included death of a family member, car accident, death or suicide of a friend, sexual abuse, and serious illness. Results indicated five factors on the Posttraumatic Growth Inventory (PTGI), which is designed to obtain an overall assessment of positive outcomes after a traumatic event. The factors include spiritual change, new possibilities, relating to others, appreciation of life, and personal strength. Moreover, the highest levels of growth were reported in the Appreciation of Life factor, and the least amount of growth was found in the Spiritual Change factor.

Lastly, Linley and Joseph (2004) have compiled a comprehensive review of those studies that empirically document adversarial growth. Specific variables associated with adversarial growth have been identified. The first variable is cognitive appraisal. This highlights that greater level of perceived threat and harm, as well as awareness and controllability of the traumatic event influence adversarial growth. The second is socio-demographic variables. Higher levels of education and income have been linked to post-traumatic growth, and studies demonstrate that women tend to experience greater levels of adversarial growth than do men, but the evidence, however, remains mixed. Another variable is personality. Survivors with characteristics such as agreeableness, conscientiousness, extraversion, hardiness, openness to experience, optimism, self-

efficacy, and higher self-esteem all reported positive growth. The fourth variable is coping. Adversarial growth is associated with problem-focused coping, emotion-focused coping, and positive religious coping. Religion is the next variable. This includes existential openness, intrinsic religiousness, and religious participation. A sixth variable is social support, entailing social support received, and social support satisfaction. Cognitive processing, in the form of rumination, intrusions and avoidance is also positively associated with post-traumatic growth. This is indicative of the cognitive processing necessary for the rebuilding of shattered assumptions and beliefs following trauma. Lastly, positive affect has also been significantly associated with adversarial growth.

With regards to clinical applications, the empirical research indicates that while the alleviation of distress does not necessarily promote growth, the experience of growth does act to promote post-event adjustment and to alleviate distress (Davis et al., 1998). Through facilitating growth, distress may be alleviated, which suggests a new avenue for potential therapeutic change in trauma survivors (Linley & Joseph, 2004). Therefore, *“traumatology research has important implications for redefining the ‘victims’ of trauma as individuals capable of positive change rather than merely surviving”* (Morris et al., 2005, p. 575).

2.9 Empirical Research on Meaning-Making after Parental Bereavement

Although the loss of a child is considered to be a traumatic life event (Figley et al., 1997; Parkes & Weiss, 1983), the trauma literature has generated little empirical research regarding bereaved parents struggle to make sense of, and find meaning in, the loss of a child. The existing literature is reviewed below.

In a study conducted by Braun and Berg (1994) that explored meaning reconstruction in the experience of parental bereavement, three phases in the process of meaning reconstruction were identified: discontinuity (threat to existing meaning structures), disorientation (shattering of existing worldview), and adjustment (reinterpretation). It was concluded that bereaved parents reinterpreted the meaning structures they had held prior

to their child's death in order to give meaning to the death. For example, that the death was a result of God's plan or a greater being who determines the course and/or events of one's life. In addition, the nature of the prior meaning structure, that is, the collection of beliefs, assumptions, values and norms that characterized their knowledge of life prior to the death, emerged as the core variable. Lastly, the ability to restore meaning after the death of a child was distinctly linked to the prior existence of a meaning structure that acknowledged that children do die.

A review of other studies (Wheeler, 2001) indicates that meaning-making after parental bereavement may come from numerous activities, including helping and educating other bereaved parents, volunteer work, and one's career, and having contact with various people such as surviving children, spouse, children born since the death, grandchildren, family members, friends and other bereaved parents. Making sense of the loss of a child may also involve changes in values and beliefs (Schwartzberg & Halgin, 1991; Wheeler, 2001). This incorporates faith in a higher power, reunion with the child in the afterlife, belief in a greater scheme, attributing the death to God's will, believing the death has some important, unknowable spiritual meaning, valuing and appreciating life and living more fully, accepting that which cannot be changed, valuing the spiritual above the materialistic, and strengthening of religious beliefs or finding new spiritual beliefs. Meaning-making also stems from remaining connected to the lost child (Wheeler, 2001; Schwartzberg & Halgin, 1991). This involves valuing time spent with the child, memories of the child, keeping the memory of the child 'alive,' talking about the child, internalizing the child, volunteer work connected with the child or the child's death, and contact with the child's friends. Lastly, parents report personal growth and positive gains from the trauma (Davis et al., 1998; Robinson, Carroll & Watson, 2005; Schwartzberg & Halgin, 1991; Wheeler, 2001) such as learning more about oneself, caring more about people, reprioritizing values, gaining wisdom, and shedding the illusion of immortality.

Empirical research has also focused on grief and its impact on prenatal attachment in a subsequent pregnancy, reporting that meaning needs to be given to the parenting role for the baby who has died, in order to move forward in attaching to the baby in the next

and Fagley (2005) posit that being appreciative facilitates and enhances feelings of well-being and life satisfaction, as well as feelings of connection to what we have, to what we experience, and to life itself. In addition, expressing appreciation to others is believed to build social bonds.

Empirical research on meaning-making after parental bereavement has utilised qualitative methods such as semi-structured interviews consisting of open-ended questions in order to yield the necessary data. Overall, the few studies conducted highlight that although the process of meaning-making is an individualistic one, it is a necessary aspect of the grieving experience. Lastly, it is important to note that a significant lack of South African studies have been generated pertaining to parental bereavement.

2.10 Conclusion

In summary, for nearly the past century standard models of mourning have been built on Freud's psychoanalytic concept of 'grief work,' where the ultimate aim of the grieving process is a severing of the attachment bond with the deceased, despite there being a lack of empirical evidence to support this theory. Since the 1980's, however, empirical studies have challenged this classic view, demonstrating that recovery from a significant loss incorporates finding a way of continuing bonds with the loved person whilst investing energy into life and other relationships. Moreover, the concept of meaning-making (cognitive mastery and renewed purpose), which is considered to be essential in adjusting to a traumatic experience, has been excluded from the traditional models of mourning. Only recently have models of mourning begun to be refined in order to accommodate and address meaning-making processes. Overall, little empirical research on meaning-making after parental bereavement has been generated, particularly in South Africa. The current study aims to address this gap.

The next chapter discusses and describes the methodology employed in the process of data collection and data analysis for this study.

CHAPTER THREE

METHODOLOGY

The following chapter begins with the research aim, followed by a discussion of the study design, sample, instruments, and procedure employed, and how the data was analyzed. Thereafter, ethical considerations are discussed.

3.1 *Research Aim*

The research aims to investigate how bereaved mothers make sense of, and cope after, the loss of a child to cancer. It aims to contribute to our knowledge of the bereavement process, and of the role of meaning-making in this process, and thus potentially to inform therapeutic work with bereaved mothers. The researcher chose to focus specifically on bereaved mothers, as men and woman grieve and cope differently after a significant loss (Doka & Davidson, 1998; Schwab, 1996), and empirical studies demonstrate that bereaved mothers are more at risk than bereaved fathers for developing a psychiatric illness (Li et al., 2005).

3.2 *Study Design*

This study is an exploratory and descriptive investigation. A case study design has been employed. Adopting a case study design allows for rich, thick descriptions of personal experience (Nisbett & Ross, 1980; Stake, 2000), as a great deal of detailed information is yielded (Barlow & Durand, 1999). This particular design is suitable for exploratory investigations because a collection of individual cases “*draws attention to the question of what can be learned*” (Stake, 2000, p. 435), as participants are intensely interviewed (Kazdin, 1981).

3.3 *Sample*

The sample consisted of ten bereaved mothers who had lost a child to cancer. The group was heterogenous in religion (1 Jewish; 8 Christian; 1 Moslem) but relatively homogenous in socioeconomic status, ranging from lower middle class to upper middle class. Nine of the participants are South African, and one is originally from Germany.

The age of the participants varied from thirty-five to seventy-six years, and the children who had died ranged in age from two and a half to forty-four years at time of death. Eight of the participants are employed whilst two are retired. Six of the participants are married (one being married for nearly fifty years and another for fifty years), three are single, and one participant is unmarried but involved in a romantic relationship. Even though all of the participants spoke English during the interview, some of the participants were bilingual (English and Afrikaans speaking).

Participation was voluntary however inclusion in the study was dependent on the criterion that the participants had lost a child to cancer more than five years ago. Had the researcher not insisted on a period of at least five years, the grief may have been too fresh and the participants would probably not have been open to being interviewed. Half of the participants had lost a child more than ten years ago- the longest period of time being eighteen and a half years ago.

According to M. Stroebe and W. Stroebe (1989), participation of bereaved participants in research studies is higher if vouched for by a trusted individual, such as personal referrals from religious groups, former participants, or medical professionals. Therefore, the researcher approached the co-ordinators of the Sunflower Fund (an organization that recruits and raises funds for bone marrow donors), Compassionate Friends (a bereavement counselling service), Nechama (a Jewish bereavement counselling service), and the Head of the Oncology Department at Red Cross Children's Hospital, in order to recruit participants. All these organizations are based in Cape Town. However, before any names were handed over, the respective co-ordinators and doctors initially contacted the potential participants to establish whether they would be interested in taking part in this study.

Thereafter, snowball sampling was employed in order to recruit further participants. The researcher asked the participants who agreed to take part in the study if they knew of anybody else whom they thought might want to partake in this study. The participants then checked whether the others wished to participate. If so, the researcher contacted

them. Snowball techniques are particularly useful for several reasons. First, this method increases the likelihood that only those participants who are suitable and appropriate for the study are recruited, and second, difficult-to-get-to populations can be reached for which population listings are not available (Breakwell, Hammond & Fife-Schaw, 1995). Two prospective participants withdrew from the study a day before being interviewed, stating that they feared the interview would be too emotionally painful and difficult. M. Stroebe and W. Stroebe (1989) assert that withdrawal is most probably explained by the sensitive nature of losing a loved one, and by the fact that bereaved individuals may have little reason to trust or share their personal feelings with an anonymous researcher.

3.4 *Instruments*

Semi-structured interviews consisting of approximately ten guiding questions were used to generate the data. This method aimed to elicit a detailed account of each participant's personal experience. It also gave the researcher and participant some flexibility, in that the researcher was able to follow up interesting avenues that emerged during the interview, and the participant was able to give a fuller account in areas of their choosing. Thus, the participant can be perceived as the expert on the subject, and is allowed the opportunity to tell his/her story (Strydom, Fouche & Delport, 2002). A pilot study was conducted with two participants to gauge whether the questions were appropriate and suitable. Minor adjustments were made where necessary thereafter.

The various questions in the interview schedule were divided into five main sections. Section A focused on gathering identifying data from the participant in order to place them in context. Section B centered on eliciting information about the deceased child—their age and date of death, a description of the child before becoming ill, and the participant's immediate thoughts after diagnosis, in order to facilitate the person starting to talk about the bereavement. The third section explored changes in the participant's self-concept as well as changes in romantic relationships, familial relationships and friendships, after the bereavement. Section D included questions on the process of meaning-making and the final section entailed finding out from the participant what they are still struggling with or what is still the hardest (see Appendix 1).

3.5 Procedure

The researcher contacted those participants who had agreed to participate in the study to set up convenient times when the interviews could be done. At this time, participants were also asked if they knew of other bereaved mothers who would be interested in being interviewed. Eight of the interviews were administered in the homes of the participants so that they could speak about such a sensitive topic in an intimate and comfortable setting. One of the participants preferred to be interviewed in the back office of her grandson's coffee shop, as her house was under renovation. The office was nonetheless quiet without any disturbances. The other participant preferred to be interviewed at work during her lunch hour because she felt that there would be too many interruptions from her children at home. A private office at work was used.

The researcher began the interview by establishing rapport with the participants. This took the form of firstly explaining how the participant was sourced; thereafter the researcher introduced himself in terms of what this study focuses on and why he is interested in this particular topic. The interview, more often than not, ended with the participant either showing the researcher family photographs scattered around their home as well as photographs and/or albums of the deceased child. The duration of the interview lasted approximately one and a half hours.

Recording equipment was used to capture the data, and then the researcher transcribed the recorded material. This procedure captured a much fuller record of the data as opposed to verbatim notes, allowing the researcher to concentrate on how the interview was proceeding (Strydom et al., 2002). Participants were informed telephonically, prior to the interview, that recording equipment would be used to capture the data. This allowed for the participant to withdraw from the study, as they might have felt uncomfortable with this procedure. Each participant was thanked telephonically, the next day, for their participation in the study.

3.6 *Data Analysis*

The data gathered was analyzed qualitatively using the method of grounded theory analysis. Grounded theory is a systematic inductive method of research whose purpose is to generate explanatory theory rather than to test or verify theory (Corbin, 1986; Glaser & Strauss, 1967; Strauss & Corbin, 1990). It aims toward unbiased data collection, as each line of text is coded into concepts, which allows for the development of categories grounded in the data, rather than using pre-selected categories identified from the literature (Charmaz, 2000; Miles & Huberman, 1994). This reduces the likelihood that the researcher's preconceived concepts will influence what is deemed important from the text. Coding transcribed interviews facilitates summarizing, amalgamating, and sorting of the data. Similarities and differences between concepts are highlighted, and similar concepts are grouped into categories. Thereafter, the method is based on the process of constant comparison between concepts that are derived from coded data, and continuous revision and refinement of codes and concepts. Constant-comparative analysis is a means of ensuring that the codes fit the data, rather than forcing the data into the codes (Strauss & Corbin, 1990; Corbin, 1986). The purpose of grounded theory data analysis is to generate a common account from all the data that is true to each individual description and points toward the phenomenon under exploration (Cochran & Claspell, 1987).

3.7 *Ethical Considerations*

3.7.1 *Issues of informed consent*

Each prospective participant was briefed about the study by both the coordinators of the various organizations and by the researcher, and they were provided the choice as to whether or not they would like to participate in this study. They were also required to sign a consent form before commencing with the interview (see Appendix 2).

3.7.2 *Confidentiality*

Once transcribed, the audio-tapes were deleted and the participants' identities were not disclosed on the transcripts. The participants in this study have remained anonymous, as they have been referred to by number. In addition, deceased children's names have also remained anonymous.

3.7.3 Risks and Benefits to Participants

Snowball sampling may serve to reduce the risk to participants, as the participants who volunteered for the study may have been fairly resilient already. However, there was a possibility that the participants might become distressed and overwhelmed with emotion during the interview. Should the interview have become too distressing, it would have been terminated. Participants were informed that they have the right to stop the interview, or withdraw from the study, at any point.

Moreover, these participants would have been referred for counselling so that further assistance and support could be provided. Even though the researcher is doing his Masters degree in Clinical Psychology, the purpose of the interview was ultimately to gather data by providing a safe and containing space for the participants to talk openly and freely. The researcher's role was not to create a therapeutic space. Therapeutic support, should it have become necessary, would have been arranged through Compassionate Friends and Nechama.

All of the participants reported that they found it beneficial and meaningful to be interviewed about the difficult experiences they have been through and to tell their story to someone who was able to listen. After the interview, all the participants thanked the researcher for taking an interest in their story. When the researcher contacted the participants the following day to thank them for agreeing to be interviewed, most of them mentioned finding the interview process at times painful but overall very useful and enlightening. This is in line with research findings that trauma survivors are seldom retraumatized by participating in research, and often find it beneficial (Newman & Kaloupek, 2004).

3.7.4 Reflexivity Issues

When the researcher is an overt participant in the data collection process and data analysis, experimenter effects or reflexivity issues need to be taken into account. In an interview, characteristics of the researcher may influence the participant's willingness to respond to, and engage with, the subject matter at hand. It is evident from the research

which has focused on interviewer effects that participants more readily self-disclose to an interviewer who they think is similar to themselves (Breakwell et al., 1995; Terre Blanche & Kelly, 1999).

The researcher has a personal bereavement experience of losing a sibling to cancer, which he disclosed at the beginning of the interviews. This proved to be helpful for the participants, as they identified with the researcher and the researcher identified with them. All of the participants stated at some point during the interview that, had the researcher not experienced some kind of bereavement, they probably would not have been as open to the interview situation. The researcher's race, sex and religion did not seem to hinder the participants from telling their story, as the subject matter was unrelated to those particular characteristics. However, with regards to the data analysis, the researcher was very curious to find out how the participants had not only coped with their loss, but also how they had made meaning- constantly comparing whether his concept and process of meaning-making differed to that of the participants. This may have influenced the researcher's understanding of the data.

The following chapter provides a comprehensive synopsis of the results that emerged from the grounded theory data analysis.

CHAPTER FOUR

RESULTS AND DISCUSSION

The results that follow describe the various themes that emerged once the collected data was analyzed using the method of grounded theory analysis. The results indicate that the participants' capacity to find meaning in, and cope after, the loss of a child to cancer occurs in many different domains. These have been organised into a number of thematic areas, each with several sub-themes. Each sub-theme is described and supported by quotations from different participants. Each theme will be discussed and located within the bereavement and trauma literature, previously reviewed in Chapter two.

4.1 *Remaining connected to the deceased child*

Participants talked about their need to remain connected to their deceased children. This took several forms. The first is talking about the deceased child to other people, which all of the participants spoke about. One participant asserted feeling angry that people were able to talk to her about her child while he was dying, but the moment he died, they stopped inquiring. It is for this reason that she makes a point of speaking about her deceased son, despite people very often making inappropriate and unhelpful comments. She refuses to pretend that her son did not exist even though he is dead. Three other participants mentioned that being open to talking about their deceased children not only keeps the child 'alive' but also assists in the adjustment and recovery process.

Participant 2: *"...I mean for me the worst thing was that nobody would talk about it...until the day [name of deceased son] died everyone you saw said how's [name of deceased son]...they wanted to know to the point that I was so exhausted I used to have an answering machine at home with a report for the day of how [name of deceased son] was doing...and then suddenly [name of deceased son] is dead and nobody wants to say anything because they don't know what to say...if I meet people I do talk about it...you know that person died but they were here...it's not like they never existed."*

Participant 4: *"...I always make a point of speaking about my daughter...to me then she is still alive."*

Participant 8: *"...I will talk to anybody. It doesn't matter who you are, if you come in and you are interested in what happened to my son, I will speak to you. I will explain to you as much as I can. It helps to talk..."*

Participant 9: *"...I was open about it and I spoke to people about it...that actually helped a lot and that is what made me such a strong person."*

The second form of remaining connected to the deceased child is internalizing the child. This takes the form of thinking about and remembering the child, as well as visiting places where the deceased child would have gone, and keeping meaningful objects as a reminder of special times spent together.

Participant 1: *"The loss of a child remains with you forever...I would not want it not to... I want her there in my thoughts often. And I don't think there's a day that goes by when I don't think about her...I want her around and I don't want her memory gone."*

Participant 3: *"...I carry him around in my heart...he's in here...I carry him around every day of my life...that's what matters."*

Participant 4: *"I like to be at places where [name of daughter] was when she was still alive."*

Participant 7: *"...we always walked along the beaches...we loved the sea. We used to be shell collectors...so I miss that. I still have all the shells. I have all of that."*

The third form is keeping the memory of the child 'alive.' Participants have achieved this by, in one case, telling their story on Carte Blanche, and also by holding fundraisers, planting gardens in memory of their deceased child, and engraving benches and displaying them in public places. For these four participants, keeping the memory of their child 'alive' involved doing something active and public.

Participant 2: *"I've got the story. Have you watched it ever? His [deceased son] interviews...It is the story where he was interviewed on Carte Blanche. Where he gives his views..."*

Participant 4: *"We have a little bench here in the garden...they [the grandchildren] always called it 'mom's garden,' we also have a bench in Kirstenbosch."*

Participant 8: *"When we celebrated his [deceased son] 21st birthday with a fundraiser, that for me was a sense of achievement...We did something positive in memory of him."*

Participant 10: *"My daughter loved flowers...I have planted a beautiful garden full of her favourite flowers...everyday it reminds me of her."*

Another way of remaining connected to the deceased child includes maintaining contact with the child's friends and/or child's friend's parents. One participant reported being friendly with her deceased daughter's friends still, after ten years. Another participant spoke about seeing her deceased daughter's friend's parents at least once a week, as the two daughters were in the same standard at school. Two bereaved mothers found it meaningful also to maintain connections with their deceased child's partner, as some children who were older were involved in a romantic relationship at the time of death. One of these participants stated how fond she is of her deceased daughter's boyfriend, as he was emotionally available and physically present throughout her illness.

Participant 1: *"He [boyfriend of deceased child] took care of her. He was there at night. He held her in his arms. He used to give her the medication...I think the world of him and we're still very much in touch."*

Participant 4: *"...she [deceased daughter] had some very, very good friends. These friends are also still our friends, we still see them, even after ten years."*

Participant 5: *"I visit [name of child's friends parents] once a week...because their eldest daughter and [name of deceased child] were very good friends...They were in the same standard at school..."*

Participant 7: *"Yes, we had a lovely stoep we sat on...We had some crayfish one night, [name of friend of deceased son] and myself. [Name of friend of deceased son] came up for my birthday..."*

The final form of remaining connected to the deceased child is displaying photographs and portraits, or watching videos/films, of the deceased child. All of the participants displayed photographs of their children either in their homes or at work, whereas two participants had portraits especially made. Interestingly, one participant placed a framed photograph of her son next to her, which she intermittently held and looked at during the interview. Three of the participants watch videos or films of their children either on their own or with other family members including surviving children, grandchildren or spouse. Furthermore, watching videos or films allowed these participants to see and hear their children whilst they were still healthy and active.

Participant 3: *"...and he was the most adorable child...let me show you a photograph of him...I've got a pretty good portrait of him...he had eyes you got lost in...he was the cutest child..."*

Participant 4: *"...and there were lots of films also of our second daughter, [name of deceased daughter]. I love to watch these films...I still watch these films. We have lots of videos also. I love to hear her voice."*

Participant 7: *"I have a beautiful portrait at home made by somebody who sat outside CNA at the mall...and she was drawing from people's photographs...It was just like he was walking into the room."*

Participant 9: *"...we have got so many videos that we have made that we treasure. If ever we feel we want to see his [deceased son] face again or anything like that, we just put on the videos and just watch him."*

The participants' strategies for remaining connected with the deceased child in the form of talking about the child, internalising the child, keeping the memory of the child 'alive,' maintaining contact with the child's friends or partners, and displaying photos of the loved ones, corroborates with previous empirical studies that have been conducted on parental bereavement (Benore & Park, 2004; Davis et al., 1998; Robinson et al., 2005; Russac et al., 2002; Wheeler, 2001). These findings challenge traditional models of the bereavement process and are more in line with recent bereavement literature, which illustrates that bereaved parents do not sever the attachment bond with, or withdraw emotional energy from, the deceased (Neimeyer, 2001). This is contrary to Freud's (1917/1957) concept of decathexis as central to 'grief work.' Instead, meaning is made by finding alternate ways of establishing continuity with loved ones (Klass, 1999; Klass et al., 1996; Kubler-Ross, 2005; Neimeyer, 2001), whilst moving on with life (Becvar, 2001; Kubler-Ross, 2005; Worden, 2003). Silverman and Klass (1996) and Schwartzberg and Halgin (1991) postulate that actively constructing an inner representation of the deceased and remaining connected with the deceased forms part of the normal grieving process.

4.2 Having contact with people and/or organizations

Having contact with people and/or organizations makes life meaningful for participants. This manifests in a number of ways. First, it manifests by having contact with surviving children. All of the participants stated that their surviving children not only provide them strength to cope with every day life but are, more often than not, the sole reason for living. Three participants talked about having to take care and raise very young children while their child was ill, which provided meaning in their lives during that difficult and painful time.

Participant 2: *"...I cope cause I have to. I'm a mom...I have children. I can't just curl up and die..."*

Participant 3: *"I just know how much I love them [surviving children]...They are my life...you have to [cope] for your children."*

Participant 5: *"I have always been very involved with my kids...I see my children nearly every day. I think if I was stuck in this flat with not being able to be as involved as I am, it would have been worse."*

Participant 9: *"My children, definitely my children... There were other children to see to. Because my baby was still young...She was only 8 months."*

Six participants find meaning in spending time with their grandchildren. One participant talked about certain mannerisms and facial expressions of her grandchild that remind her of her deceased daughter. Another participant mentioned that having contact with her grandchildren not only keeps her occupied but also makes her life fuller and richer.

Participant 1: *"I mean I've gotta be fine for my children. I've gotta be fine for my grandchildren."*

Participant 4: *"We also have a good relationship with our grandchildren...They love to come visit, and phone...We are often with my grandchildren and I say 'You just laughed now like your mom used to,' and she loves it..."*

Participant 5: *"The saving grace was on the day [name of deceased daughter] was buried my first grandchild was born...It is not a replacement but it keeps me busy."*

Participant 6: *"We keep in contact with her [deceased daughter's] children and they know that they are loved by us and that we are here for them if they need us."*

Six participants find it meaningful to have contact with their respective spouse or partner, describing their husbands or partners as supportive and loving, equating them to their best friend. Four participants describe becoming even closer to their husbands, as a result of losing their child.

Participant 3: *"...he is my best friend...he deals more with [name of deceased son] with me than anybody could possibly know...it's the most extraordinary thing..."*

Participant 6: *"...I adore him [husband], I love him very much. We have been through a lot through the years...if you can sit and chat about your differences...and you don't go to bed angry, I think that to me is the biggest thing."*

Participant 8: *"...we are best buddies...I am very grateful for him [husband], for his support because we are very close..."*

Participant 9: *"...with myself and my husband we have become so much closer...We have been there for one another."*

Participants also find meaning in having ongoing contact with family members. Five participants described family members as being not only helpful but also supportive during their child's illness and post loss. For these participants, knowing that they were able to rely on family members for emotional support provided great comfort and relief. Two participants mentioned becoming even closer to certain family members.

Participant 3: *"I have one sister who I am close to...she was a tremendous help to me...if anything we bonded closer..."*

Participant 5: *"We were always a close-knit family so I can't say [name of deceased daughter's] illness brought us together. It made us a lot tighter."*

Participant 8: *"I must say the family really came up...Just one phone call and everyone was there."*

Participant 9: *"...We have a close-knit family and the support that they gave us was just amazing...They are always there. At any point if we feel down, we can always turn to them for anything. That was actually a bonus."*

Meaning is also made through having contact with friends. For two participants, friends were the only social support networks available, as members of the family were either deceased or lived abroad. Three other participants found it more helpful and useful to speak to close friends than to family members, as they were less judgmental and more understanding and supportive of the grieving process. These participants found that family members would hurry them along or would want to rush them through the grieving process without allowing them to take the necessary time needed to grieve. Four participants mentioned establishing good friendships other than with bereaved parents, as a result of spending so much time at the hospital during their child's treatment.

Participant 2: *"My support structure were my friends...I had my friends that helped and did things and filled in whatever I needed."*

Participant 3: *"But it does help...my friends are friends that I have had for years and they just stay...and the people who couldn't deal with it who have moved on I wouldn't want as friends anyway..."*

Participant 8: *"We have met a lot of people through Red Cross...We have made fantastic friends. In fact you meet the wider community and the family, not just that couple and their children."*

Participant 10: *"Fortunately you can choose your friends...I have some very close friends who are incredibly understanding and supportive...Thank God for them."*

Eight participants talked about keeping contact with other bereaved parents. This kind of contact is helpful, as bereaved mothers feel less lonely and isolated in their grief and instead feel understood, heard and supported. Three participants were adamant about only wanting to talk to other bereaved mothers once their child had died. Spending extended periods of time at the hospital enabled participants to meet, talk to, and connect with, other bereaved mothers, and to share their pain. Interestingly, two of the participants mentioned that they would not have been so open to the interview and able to talk so freely had the researcher not gone through his own personal family bereavement. All of the participants specifically stated that they were eager to be part of this study and talk about their children knowing that it may benefit other bereaved mothers.

Participant 3: *"...[name of bereaved parent] is also a very good friend...We were at the same school together...she was in so much pain...I knew that we could help each other..."*

Participant 4: *"I think actually nobody can really understand it, only the person who it happened to can. We knew some people who also lost a daughter and we could talk more easily with them."*

Participant 8: *"You meet those people- mommies and daddies -who are going through traumatic times and they are appreciative of the fact that you know what you are talking about so they need you. They don't want somebody who doesn't know."*

Participant 9: *"...what also helped was having somebody out there who had gone through the same thing. Especially like the children who were hospitalized at the time when [name of deceased son] was in hospital, we have actually become connected with the parents there...I always tell them 'pick up the phone, I am there, I can relate to what you are going through.'"*

Lastly, participants also find it meaningful to have contact with professional organizations or staff from the hospital. One participant ended up befriending and

becoming close to some of the medical staff at the hospital, as her son was ill for a period of two years. Three participants stressed the importance and benefit of having contact during the early stages of grief with organizations such as Compassionate Friends and Hospice, as they were not only supportive but also assisted in the initial stages of the mourning process.

Participant 3: *"...I have been surrounded by the most incredibly loving, compassionate people...friends that you make at the hospital...the entire nursing staff and doctors came to his [deceased son's] funeral...the one doctor I became good friends with..."*

Participant 4: *"I went to the Compassionate Friends group...I still get the little newspaper, and I read through it... some articles I think are really good."*

Participant 6: *"They are very supportive...I found that the sisters at the Hospice were very, very good. They would sit and chat to you. ...I think you do need to have support. You need somebody to talk to...the cancer support sisters used to phone us quite regularly for 3 to 4 months after that...every year she [one of the cancer sisters] sends us a Christmas card..."*

Participant 7: *"I had Hospice down the last couple of weeks for him [deceased son]...after your child dies they get someone to come speak to you. She came down twice a month, for about 18 months, and you cry. It does help. They tell you to write a letter to them about what is happening and how you felt..."*

Thus, having contact with various people and/or organizations illustrates that mourning is not a private and intrapsychic process, as historically conceptualised by Freud's (1917/1957) psychoanalytic model, but is profoundly social and relational (Neimeyer, 2001). According to Stolorow and Atwood (1992), meaningful connections with others play a significant role in facilitating or hindering recovery from bereavement. Moreover, results from an empirical study generated by Wheeler (2001) indicate that the most cited domain of meaning-making for bereaved parents was meaningful contact with people.

This included surviving children, grandchildren, spouse, family, friends, and other bereaved parents. In addition, other empirical studies confirm that bereaved parents have a strong need for supportive contact from hospital staff during the palliative phase and following the death of a child (Clerici, Ferrari, Massimino et al., 2006; Dean et al., 2005; Monterosso, deCinque, Dadd et al., 2006), which was reported by three of the participants in this study.

4.3 *Fulfilling activities*

Participants spoke about occupying their time with fulfilling and meaningful activities. This involves either pursuing a career or doing volunteer work connected with the child, or doing general volunteer work by means of giving back to the community. Six participants had done, and some still do, volunteer work connected to the child, including being involved in organizations such as the Sunflower Fund, Red Cross Children's Hospital, and Nechama (Jewish bereavement counselling service). One of these six participants explained how doing volunteer work for the Sunflower Fund allows her to keep her connection with her deceased child and with other bereaved mothers who are in the same situation. Another mentioned becoming a trained Nechama counsellor dealing with a variety of cases, which she finds extremely rewarding and fulfilling. Another two participants filled their time doing general volunteer work at various organizations like the Union of Jewish Women, the Holocaust Museum, Marsh Memorial Children's Home, Rape Crisis, and Night Shelters. One of these two participants, who is retired, described how doing volunteer work keeps her busy, and that the most satisfying way of occupying her time is to give back to the community.

Participant 1: *"I did a huge amount of work for the Union of Jewish Women...I joined the Holocaust Museum this year and I've been trained to be a guide...that I like very much. At the moment, I'm writing a cookery book...I managed to do lots of things. A lot of good things, with my life."*

Participant 2: *"...I run the [name of organization] for recruiting bone marrow donors. I deal with people. I deal with parents. I deal with people losing people...it's become my life..."*

Participant 3: *"...you know I did quite a lot of work for the Sunflower Fund...and I would do anything to help because you want to keep your connection...obviously when you have had such a personal connection with the disease and the whole situation..."*

Participant 7: *"I do a lot of voluntary work at Red Cross and Marsh Memorial Children's Home. I collect a lot of stuff to take to the Night Shelter and Rape Crisis...We also gave underprivileged people a luncheon...That is how I keep myself busy...There are lots of things I help with."*

Another meaningful activity entails helping or educating other bereaved parents. Five participants reported counselling mothers through the palliative phase, supporting other bereaved mothers post-loss, and helping mothers become aware of the signs and symptoms of childhood cancer when their children complain of physical problems. One of these five participants categorically stated that her number one priority was helping other bereaved mothers in whatever way she could, and that was her way of answering the fundamental question, 'Why us?'

Participant 2: *"...I counsel people sometimes, I wouldn't counsel them on...in an area that I didn't know about...on an eating disorder or something...But in this field, I know I can support them, probably sometimes better than somebody who just knew the theory."*

Participant 8: *"...you always ask the question 'Why us?' and the answer always came 'because we can help other people going through the same as us.' Helping other people is our priority. It is my priority."*

Participant 9: *"...I always tell people what the signs are to look out for and never just to think that your child is lazy and ignore him complaining constantly of something. I try to*

be of help to others...educate other parents...who might not have any knowledge of it [cancer]."

Participant 10: *"For a while quite a number of my clients were loss and bereavement cases...Through working on myself and dealing with my own grief, I was more able and less afraid of helping others deal with theirs..."*

Participants' search for renewed purpose may involve transforming the trauma of their loss into altruistic acts, thus providing benefit for others (Janoff-Bulman, 1992; Neimeyer, 2001; Tedeschi & Calhoun, 1995). Occupying one's time with fulfilling and meaningful activities gives participants a sense of purpose, which is in line with previous research findings (Davis et al., 1998; Frankl, 1978; Kushner, 1982). Empirical research verifies that meaning-making after parental bereavement may come from activities, for example career, volunteer work, helping other bereaved parents, and educating bereaved parents about grief (Wheeler, 2001).

4.4 Changes in spiritual and/or religious beliefs

Participants reported changes in spiritual and/or religious beliefs after losing their children to cancer, in an attempt to make sense of such a traumatic life event, which shatters fundamental assumptions and core beliefs. These changes manifest in various ways. Four participants find it meaningful and comforting to believe in an afterlife, that their son/daughter is in a 'better place,' and that they will be reunified with their deceased child when they die.

Participant 2: *"I always figure maybe and I suppose this is sort of the spiritual side coming in...Maybe when I die...You meet all these guys again and suddenly everything makes sense."*

Participant 3: *"With [name of deceased son] he is in a place for me where...but where ever he is it is surely better...but we are all going there...somehow...sometime..."*

Participant 4: *"I think there is life after death- I hope there is. I want to hope there is."*

Participant 9: *"We believe that there is life after death...knowing that we will be reunited one day, does help...The day of my son's burial, the Imam said to us 'this child is going straight to heaven and he will stand at those gates waiting for his parents.'"*

Another way in which four participants make sense of losing their children is to believe in a greater scheme or bigger picture. Two participants described a greater scheme as the wheel of life, or as a whole big energy dynamic. For two other participants, the bigger picture meant that there was a fixed time when each of us will die, which is out of our control, or that God has his unique ways of working and reasons for doing things.

Participant 2: *"Uhm...I mean the bigger picture of how the world works, the whole dynamic is one thing...there is this whole big energy out there..."*

Participant 3: *"...it's all part of the big picture...that I believe...I really do believe...I don't know if you have read Elisabeth Kubler-Ross, The Wheel of Life, it has meant more to me than any other book..."*

Participant 4: *"I think that there is perhaps a time when somebody says '...now is your time to die' but in between we live our own lives...once we are in this world we make our own life..."*

Participant 9: *"...God has got his ways of working and there is a reason why this probably happened. We might not know now what the reason is, but we will eventually find out..."*

Five participants also find it meaningful and helpful to have faith in a higher power. Three participants referred to this higher power as a creator, a Higher Being, or Him. Having faith in a higher power seems to give participants permission to trust in the process of life and to surrender to the way in which this power works. For some

participants the higher power was God but for others it was not. Having faith in a higher power differs from believing in the greater scheme, discussed above, in that some of those participants who believed in the bigger picture did not necessarily believe in a higher power or God but were, rather, more spiritual.

Participant 3: *"...somewhere in the back of my mind I think there must be a higher being...a creator...yah...there has to be..."*

Participant 4: *"I think there must be somewhere a power, which started everything and holds it somehow together...But I think there is a power on the whole."*

Participant 6: *"...there is a Higher Being...He determines your destiny, what you are going to be, what you are going to do, what is going to happen to you."*

Participant 9: *"...I feel that I can turn to Him about anything. I speak to Him when I am confused about something and then things become so much clearer...I thank Him for every day for what I have...What I do is pray on [name of deceased son] that he be in the best place in heaven, the highest place is in heaven and send my regards to him..."*

Four participants temporarily believed that the death of their children might have been a form of indirect punishment, as it was their initial way of attempting to explain and make sense of, such a traumatic event. These participants employed this belief as a meaning-making strategy in the early stages of their grief but soon abandoned this notion.

Participant 2: *"There's a lot of things in life that you think hey give me a break. I've dealt with a lot in my life other than this, and I thought, you know I joke and I say maybe I was a serial killer in my past life...if there is this whole thing about things coming back at you...I must have been a very evil person. But I don't like to believe that, cause then why was [name of deceased son] punished, if that's gonna be the theory..."*

Participant 3: *"...I was involved before, for five years but he [previous boyfriend] tried to commit suicide and then now I have left [name of husband]...and my therapist thinks there could be a correlation to [name of deceased son] and my leaving my husband...I wonder if I was punished in this life because of the road that I was going to take...I don't know...it's very difficult to work it out..."*

Participant 6: *"You wonder whether you have done something really bad in your life that you are being punished for it but I don't really think that way because I think God is a very forgiving God and if you are sorry for what you have done during your life, you ask God for forgiveness...if you haven't gone and done the same thing again, to me then it is alright...I believe you will die and go to a place where everybody will be judged...You have got to make it right, now. Now is the time to make things right."*

Participant 10: *"It did pass my mind in the beginning that maybe I was being punished in this life for being a bad person in a previous life...but I don't really believe that...I suppose it was just my way of trying to make sense of this whole thing, and a way of finding answers but there aren't any, really...who knows why these things happen..."*

Participants find it meaningful to alter their religious beliefs by believing less or not at all in God or religion, thereby becoming more spiritual. Three participants describe religion as being contradictory, man-made, controlling, and an unhealthy crutch. Interestingly, five participants who were not religious prior to the death of their son/daughter questioned or abandoned their faith, and believed even less in religion post-loss.

Participant 1: *"There's so many contradictions...I have never come across a rabbi that I can relate to...I don't know if I believe in God...You know, I don't come from a religious background."*

Participant 2: *"...I don't believe in religion. I think it's man-made...I don't go to Church...I didn't grow up in a religious family. I think also with everything we went through, I questioned a lot of stuff...I think there is a god and there's a spirituality...to*

control people...it puts people into groups and it causes more trouble than anything else actually, religion...my own background is Catholic, which is a whole load of rubbish...I don't believe in all of that. Some person has made up all those rules..."

Participant 3: *"...after he [deceased son] died for a while but I think from then on, I questioned my belief in religion. I questioned particularly religion rather than anything spiritual, it's religion that I'm not comfortable with."*

Participant 4: *"It [religious beliefs] went less, I would say because I could somehow not really understand if there...how can I say this...I believe in something but I believe in a different way to the way that they preach it in Church...where I feel comfortable with my own beliefs."*

However, for those participants who already had a strong religious foundation, their religious beliefs were strengthened after the loss of their children. These five participants used religion to find meaning in the loss and to gain solace and emotional strength. Three participants talked about prayer and faith in God being a powerful coping mechanism during the grieving process. Furthermore, four participants also asserted feeling grateful that God was able to provide relief from their children's suffering, thereby taking their children to a 'safe' place to rest.

Participant 6: *"...if I hadn't of had God in my life, I don't think I would have been strong for her [deceased daughter], I really wouldn't have because you always know there is somebody else who you can pull your strength from, even though you can't see Him but He is all around you...I think if you are strong in your beliefs and your way of living, the world shouldn't worry you that much"*

Participant 8: *"...it [religion] is the one thing that carried me and [name of husband] through our period of trial and tribulation...a lot of prayer carried us through...that your faith can carry you through...I think that is the only thing that was right for me at the time and the fact that I knew [name of deceased son] was going to be safe..."*

Participant 9: *“With the loss of my son, I think that has made us even more religious...You turn to God, you turn to prayers and that actually helped us because you know there was nobody better to speak to than the One above...Just the mere fact knowing that he is in heaven and he is resting without pain...that actually takes so much weight off your shoulders.”*

Participant 10: *“Over the years I have become even more observant...and I have come to learn that God did not take my daughter away, cancer did...I was angry at the disease for a long time...God provided relief from the suffering.”*

Since parental bereavement is a crisis of meaning (Braun & Berg, 1994; Miles & Crandall, 1983; Wheeler, 2001), which challenges prior core beliefs and violates previous unquestioned assumptions, bereaved parents may be vulnerable to the loss of cognitive mastery (meaning-as-comprehensibility) (Janoff-Bulman, 1992; Tedeschi & Calhoun, 1995). It is for this reason that Worden (2003) reiterates the importance of spiritual adjustment that the bereaved need to make in order to move through the third task of mourning, as religious and/or spiritual beliefs are not only reviewed and modified but also perhaps changed (Simons, 1979).

Empirical studies demonstrate that meaning-making after parental bereavement may involve changes in religious and/or spiritual beliefs. This takes several forms. For example, faith in a higher power, belief in a greater scheme, reunion with the child, belief in an afterlife, strengthened or weakened religious beliefs, finding new religious and/or spiritual beliefs, and believing that the death is some form of indirect punishment (Braun & Berg, 1994; Cardella & Friedlander, 2004; Davis et al., 1998; Linley & Joseph, 2004; McIntosh et al., 1993; Schwartzberg & Halgin, 1991; Staudacher, 1987; Tedeschi & Calhoun, 1995, 2004; Wheeler, 2001). This empirical research was confirmed by all of the participants to varying degrees, in this particular study.

Moreover, Schwartzberg and Halgin (1991) posit three changes in religious and/or spiritual beliefs that are likely to occur after parental bereavement. First, bereaved

individuals who had a strong religious foundation prior to the loss could become more religious post-loss. Second, bereaved individuals who did not have a strong religious faith prior to the loss may abandon their faith or become even less believing after their loss, and thirdly bereaved individuals who were not religious prior to the loss may become religious post-loss. The first and second changes clearly applied to eight participants in this study, however not the third change.

4.5 *Seeking professional help*

Participants spoke about the benefit of seeking professional help. Five participants found and some still continue to find it helpful to attend individual psychotherapy or Compassionate Friends support groups. One of the participants who has been attending Compassionate Friends for almost fourteen years described that even though she is mostly quiet during the group session, listening to other bereaved parents makes her feel less alone and isolated in her grief. Another participant talked about seeing a therapist during her son's illness, which she found very useful. One other participant thought, as a result of seeing a therapist and working on herself that there might be a link between her current divorce and son's death. On the contrary, another participant mentioned how her marriage with her husband was saved as a result of seeking professional help, and that perseverance is key in the grieving process. Overall, these participants reported seeing a psychologist to be a significant factor in their adjustment and ability to cope post-loss.

Participant 1: *"...then I was seeing [name of therapist]...and I kept going to [name of therapist]...much improvement. Perseverance...[Name of therapist] helped me a lot...she was a big help...she saved my marriage."*

Participant 2: *"I've been on and off. Uhm...I still see somebody. It helps me with my job...it helps me to see somebody, for myself. You know, while [name of deceased son] was sick, I saw somebody..."*

Participant 3: *"I've been seeing a psychologist just for a while, and she's very keen to go through the death of [name of deceased son] again...but what I think she was trying to*

say to me was possibly the death of [name of deceased son] has some correlation between me leaving [name of husband] this year...I mean I found it fascinating. It does help..."

Participant 7: *"It might even have been in 1993 because one of the ladies from our church came to me and said 'come on. I want you to come to Compassionate Friends with me.' I go once a month- the third Monday of the month. I find it helpful just to listen to others."*

According to Schwartzberg and Halgin (1991), grieving individuals often seek professional assistance to help relieve their pain because *"nothing in their history has prepared them for the intensity, nature, and duration of the emotions and changes they are experiencing"* (p. 244). Clinicians are also able to facilitate the meaning-making process by assisting the bereaved in gaining some understanding of the myriad of cognitive and emotional changes they are experiencing (Schwartzberg & Halgin, 1991). Although many empirical studies demonstrate that men and women express grief differently (Bohannon, 1990; Littlefield & Rushton, 1986), bereavement literature suggests that it is more useful to focus on the difference between the principles of 'feminine' and 'masculine' grief, as not all women are feminine grievers, and not all males are masculine grievers (Doka & Davidson, 1998). Five participants in this study fit with notions of feminine grief, such as expressing and sharing their feelings with others, and being open to receiving individual and group psychotherapy (Doka & Davidson, 1998).

4.6 Positive psychological growth from the trauma

Participants reported positive psychological growth in several domains after the trauma of losing a child. Firstly, this includes reorganized values. For five participants reorganizing values manifested through changing from superficial to more authentic and real friends, valuing health over material items or wealth, and not taking people for granted, as life has become uncertain and unpredictable.

Participant 2: *"...I just think there are bigger things that are important...I've changed a lot of my friends...my closer friends are quite real people. Before I had a lot of good, harmless friends but very material, superficial, stressing about every little thing...The big things are important the little things aren't."*

Participant 4: *"...they [surviving children] put a lot of value on material things in this life and I think if you haven't got your health...I thank God everyday for my health...if you haven't got your health, what have you got?"*

Participant 8: *"...wealth cannot buy us our health so it is not important. It is important to see you through every day, to cover your costs, to cover your living, to cover whatever but it is not important if you don't have it...It is not an issue. It is nice but it mustn't be the beginning and end of your universe."*

Participant 9: *"When I look at people and I think how they can just take things for granted, I always tell them 'never take things for granted there might not be a tomorrow. Never take anything for granted.'"*

Participants also find it helpful and meaningful to view the death in perspective. Given the extremely violent and dangerous context in which many South African's live nowadays, five of the participants were grateful and relieved that their children died in the way in which they did. With an expected death at least there was the opportunity to say goodbye properly, and time to prepare for death. Participants explained that viewing the death in perspective did not make the loss any less painful but it did allow them to compare themselves to other bereaved parents and to see that the circumstances could have been so much more horrific. Viewing the death in perspective also helped participants not to feel alone or isolated in their suffering.

Participant 1: *"...if you look behind the closed doors, almost everyone's got a problem...A few months ago...I had some people over for supper...and [name of friend] said to me you know [name of participant] four of us here have lost a child...and [name*

of friend] lost his child under the most terrible circumstances...and you must see how [name of friend] gets through life. So people do it."

Participant 3: *"When I look around and I see what other people go through...I just have to look at the television, pick up the newspaper. I am no worse off...I mean I was in a ward with a woman who lost both her children...a son and a daughter to some sort of familial tumor...and she lost them both within two years of one another...it could happen to anyone...from any walk of life...any religion, any socioeconomic level."*

Participant 7: *"I also often think if he still would be working in town he might even have been murdered by now with the way things are going...I wouldn't want him to be murdered. Last month my grandson was hijacked...These things happen to so many people and especially in the last few years, 3 or 4 matriculants were killed in a car accident...There is a lot of cancer. Everybody you talk to knows someone who is dying of cancer."*

Participant 10: *"I am actually relieved and grateful that my daughter died the way that she did...she could have been shot or murdered...society has become so incredibly violent...at least with cancer we had time to prepare for her death and say goodbye..."*

Positive psychological growth also took the form of appreciating people and life, and the little things in life. Seven participants reported becoming more appreciative of the natural beauty around them, their surviving children, and of their own life. They also described learning to live in the present moment because nothing is permanent, and life is too short.

Participant 5: *"I appreciate them [surviving children] more. I think realizing nothing is permanent makes you appreciate things more...say what you want to say, don't leave it."*

Participant 6: *"I think you also learn to appreciate the beauty around you that you know man can't make...for instance flowers- like that flower there, somebody gave us the bulb for our anniversary present. That plant has had 13 big flowers on it. Now to me that was*

given with a lot of love...They also gave us some glasses. The glasses I have put in the cupboard but to me that [the flower] has given me so much pleasure, because it is also one of God's creations. I just take a lot of pleasure in looking at it grow."

Participant 8: *"...you value your life and the time that you have. We don't know how much time we have on this earth. We have realized life is so short. It is here today, gone tomorrow...That is a big thing for me, to be grateful for the little things."*

Participant 9: *"I think I just live now like each day is the last day. I value life. I live like every moment that you have, you must make the most of...you realize the value of life. It is very important..."*

Six participants talked about becoming more caring and compassionate, as well as a stronger person, post-loss. Becoming a more caring and compassionate person seems to have emerged from participants having to face and confront their own pain, and as a result being more aware of other people's pain and having a greater capacity to empathize with, and understand others. One participant described becoming stronger in the sense that if she could deal with a traumatic life event such as losing her child then she could probably deal with most events that life might throw her way, and they would be considered mild in comparison. Another participant explained that strength also came from being able to manage concurrent personal stressors at the time of losing her child.

Participant 6: *"Knowing that she [mother of participant who died of cancer] had suffered and then seeing [name of deceased daughter] suffering and then nursing somebody [sister of participant] who also had cancer ...I think it made me stronger inside...I think I have also become more compassionate towards others that are going through something like this, like this friend of mine who lost her daughter through a massive heart attack...I talked to her more than what I would have done before."*

Participant 7: *"I am concerned for [name of friend]. She has gone through a terrible time. Her husband died about 2 months ago and she had to look after him. He had*

prostate cancer and then it went to one lung. He got very bad...You have to be there and also it teaches you compassion...What I have gone through has made me very aware of other people."

Participant 8: *"...when I see someone else who has a Leukemia diagnosis...you feel for the moms because you know exactly what they are going through because you have been there...I will be there for them emotionally and otherwise. I will pick up the phone and I will say 'How are you doing?' That is what we are here for, to be there for one another..."*

Participant 9: *"...even after having lost him [deceased son], we have become so much better people...I have become stronger emotionally to deal with things. I feel I can actually deal with anything that comes my way...That is the good thing about it all. There is always something positive that comes out of something like this..."*

Trauma literature and empirical research illustrate that a major component of meaning-making in the aftermath of a traumatic life event such as parental bereavement is the search for renewed purpose (meaning-as-significance) (Frankl, 1978). This includes perceived psychological growth (Linley & Joseph, 2004), or positive outcomes (Janoff-Bulman, 1992), which may take several forms. The first is important lessons learnt involving either a newfound appreciation of life or of oneself. The second is benefits for oneself such as being a more caring and compassionate person as well as an enhanced sense of personal strength. Another form is improvements in relationships with others including greater emotional intimacy, and lastly a changed philosophy of life. This entails value reorganization and reordered priorities (Janoff-Bulman, 1992; Neimeyer, 2001; Tedeschi & Calhoun, 1995, 2004). Results from this study confirm the above-mentioned literature and empirical findings.

However the analysis in this study revealed another sub-theme related to meaning-as-significance, namely viewing the death in perspective. Viewing the death in perspective led four participants to be not only more grateful and thankful in terms of the manner in

which their children died but it also brought a sense of relief knowing that, considering the South African context, the death could have been much more shocking and horrific. The researcher felt that participant's ability to view the death in this way, from a realistic perspective was helpful, positive, and meaningful and did not constitute minimizing the disruptive impact of the loss by downplaying the emotional pain.

4.7 Complexities surrounding parental bereavement

Certain complexities arise that are not only particularly related to losing a child, but also to losing a child to a malignant disease such as cancer. One of these complexities involves the senselessness and unnaturalness of the death of a child. All of the participants spoke about the unnaturalness of child death, and that the idea of a child becoming sick and dying is senseless. Participants explained the unnaturalness in that child death reverses the natural order of life events, and that it is just wrong burying a child. One participant stated that one should die when one is old, not at a young age, and that one is conditioned to believe that that is how the world should work.

Participant 1: *"...I can't make sense of it. To me it's senseless. For a mother to just lose her kid...and bury a child...that's senseless...It should never happen to a parent. It's too terrible...I should be like every other mother, you know..."*

Participant 2: *"...one sure thing is that we all know we're all gonna die...but not at seventeen...you can't make sense of that. And it doesn't...cos the world...the world we're brought up in, people are born and they grow up and when you're old, you die. And when the other thing happens, it's wrong...and I can't answer the question why."*

Participant 6: *"...it was easy for people to say 'our deepest sympathy' and 'we feel sorry for you' but they hadn't lost anybody, they hadn't lost a child. You feel, as a parent, it is also unfair because you as the parent are supposed to die not your child. That is grossly unfair because it is just not part of the make-up."*

Participant 10: *"...that for me was the hardest part to resolve...the untimely nature of child death... my daughter should still be here...it feels wrong that she died before me...it is not the natural order..."*

Another complexity surrounding parental bereavement, particularly losing a child to cancer, is the effect that an expected death has on bereaved mothers. Results were mixed. Three participants talked about the difficulty of witnessing their children suffer and slowly die in front of them, and the complete helplessness associated with that, even though there may be the luxury of time in order to prepare for the impending death. Three other participants were very grateful for the preparatory time that they had with their children prior to their death, as little unfinished emotional business was left unattended, that is, they had the chance to say 'goodbye' and 'I love you.'

Participant 4: *"...when you read the newspaper, you read about what people died of. Many are accidents and a few die of cancer. I know every death is terrible and with accidents you have the terrible shock and you are completely unprepared. With cancer they always say you are prepared but for me it was such a sad period to see somebody die slowly..."*

Participant 6: *"...I felt very sad when I was helping to nurse her [deceased daughter], because sitting there at night and knowing that you could do nothing. I couldn't wish for her to stay alive, seeing her suffering like that and knowing that nothing could be done, no medicine, no doctor, no nothing...the bible says there is no pain, no suffering when you leave this earth, for me that is my sort of bonus..."*

Participant 8: *"For me being told that [name of deceased son] only had a short period of time helped me prepare...That was a plus for me because the mourning started already way back before the time...But it is still a shock when it does happen obviously because nothing prepares one for that."*

Participant 10: *"I am so grateful for the time that we had together while she [deceased daughter] was dying...the time that we had together was so important and valuable...there are no regrets...nothing was left unsaid...I told her that I loved her many times and we said our goodbyes...she died peacefully."*

Bereavement and trauma literature highlight that not only is parental bereavement considered to be the most grievous and traumatic of losses (Miles, 1985; Sanders, 1980; Videka-Sherman, 1982) but also differs from other types of losses in the following way. Parental bereavement is particularly difficult to resolve and even more difficult to make sense of, as the loss of a child is seen as an untimely and unnatural life event (Rosen, 1988), which all of the participants in this study confirmed. Child death reverses the sequence and natural order of life events for bereaved parents, regardless of the age of the child (Gorer, 1965). All of the participants were able to comprehend that people die of malignant diseases but they struggled to make sense of why a child has to die in this way. Despite this, they were able to find meaning in the aftermath of the loss in terms of renewed purpose and growth into a more adaptable human being with improved coping skills and an enhanced sense of self-worth. This finding is contrary to the notion proposed by Janoff-Bulman and McPherson (1997) that successful adaptation post-loss involves first cognitive mastery before renewed purpose in life can be achieved.

Another complexity surrounding childhood death due to a malignant disease, in particular, is a sense of failure on behalf of parents being unable to have controlled their child's fate (Rando, 1986). On some level, bereaved parents feel that they should have protected their child from pain and ultimately from death, resulting in them feeling helpless (Sanders, 1982; Staudacher, 1987). An anticipated death on the one hand affords parents the time to take care of unfinished emotional business (Worden, 2003), but on the other hand causes distress in itself (Attig, 1996; Norris & Murrell, 1987), as parents may witness a loved one suffer from an extended illness (Becvar, 2001; Worden, 2003).

Results from this study were also mixed regarding participants' feelings about an expected death to cancer. Four participants reported feeling helpless as they watched their

children suffer and slowly die, whereas six participants were only too grateful that their children died in the way in which they did, as an advance warning of a pending death left little room for subsequent regrets.

4.8 *Ongoing difficulties that bereaved mothers endure*

Four participants reported ongoing difficulties or struggles since having lost their children to cancer. This includes neglecting, or being physically and emotionally unavailable to, surviving children when their child was ill and post-loss during the mourning process, and the effect this had on their children in later life. One participant spoke about her daughter having to become a parental child looking after her sibling, whilst her mother was at the hospital with her brother. This participant felt that her daughter was emotionally overburdened at too young an age, and that she was forced into a role where she had to take on too much responsibility, which seems to be causing difficulties now. Another participant talked about the tremendous guilt that she still feels for having left her healthy children at home whilst she was in and out of hospital for two years when her son was sick. One other participant also stated not having the physical and emotional strength to mother surviving children, as she was so immersed in her grieving process, feeling very sad for a long time post-loss. As a result, her surviving children had to parent themselves.

Participant 2: *"So my kids...they didn't have me completely as a mother. She [surviving daughter] didn't have me enough, which has caused enough problems now for her, cause she had to grow up way to quickly...at that age to be responsible..."*

Participant 3: *"...and you know you feel such guilt towards the little healthy one you've left at home...I can feel indescribable remorse...guilt...even depression sometimes...the guilt is a huge thing...I mean you do say please please please let me take it away from him [deceased son]...let me have it not my son."*

Participant 9: *"He [deceased son] suffered with Leukemia for 4 years, so during those 4 years we had no life...I gave birth to my baby just before he [deceased son] had a bone*

marrow transplant and was in remission. She [surviving daughter] has been away from me for almost most of her time because I spent most of my time in the hospital, myself and my husband, we spent most of our time away from the other two."

Participant 10: *"For a long time, I was so immersed in my own grief that I stopped being mother to my other children...I was so sad for such a long time...I did not have the will nor the strength to be there emotionally for my other children...It is like my children had to look after themselves..."*

Another ongoing difficulty that four participants mentioned was becoming overprotective and/or fearing the death of surviving children. One participant spoke about preferring to keep her children indoors, and to rather let friends visit their home, as well as wanting to know who her children are spending time with. Another participant asserted feeling anxious when she has not spoken to her children telephonically for a little while, thinking the worst that something terrible has occurred.

Participant 3: *"Well I could very positively say I have got an anxiety...probably over anxious...I mean [name of surviving son] is a wild child and I am so terrified that he is going to die one way or another."*

Participant 8: *"After he [deceased son] died I became, I think, a little more neurotic with the others [surviving children]...and I think I still have that fear."*

Participant 9: *"I am very protective of my children...We prefer keeping them indoors...you know how the world is today with drugs and things like that... so we prefer to keep them indoors, playing with the play station and keeping them occupied in that way, with computers, watching videos, and if there are friends, we let them come over to our place. We want to know who they are with..."*

Participant 10: *"I still get very worried about my children and feel overprotective...even though they are much older now. When my kids have not called for a while to say hi, I*

start to panic...I think to myself that maybe something terrible has happened to them...I always think of the worst."

All of the participants mentioned that they have learnt to live with losing their children, but that the loss is ongoing, and will remain with them until they die. One participant asserted that even though she gets on with life, she would never get over the loss. Two participants stressed that other people often make comments such as 'it will get better with time' or 'you should be over it now' but these comments are unhelpful and often come from people who have not lost a child themselves.

Participant 2: *"You never get over it...never ever...People say things like...especially in the early days...it will get better with time...it's the biggest joke...and the people that say that are only people that have never been there...it's like a thing they say cause they've heard it...you just learn to live with it...you get on with life but you don't get over it..."*

Participant 4: *"I must say after five years it was a bit better. Now after ten years I can look forward to things again but it takes a long, long time...you have to learn to live with it..."*

Participant 7: *"Other people say 'oh, you should be over it now.' You can't, not a child, you cannot. It is inside you..."*

Participant 8: *"When you are in that situation, there is nothing you can do but learn to live with it. There is nothing that you can do. You have to accept, and you have to take one day at a time and live with it..."*

Previous research reports that, for mothers, caring for their sick child results in severe role strain by compromising their emotional and physical capacity to function in other roles, such as their role as mother to surviving children (Young et al., 2002). Results from four of the participants in this study corroborate this finding, indicating the strain that is placed on the role of mother, whilst taking care of a sick child. Moreover, the loss of a

child moulds surviving parent-child relationships, as parents not only become over-protective (Malkinson & Bar-Tur, 2004) but also fear surviving children becoming sick and perhaps dying (Staudacher, 1987). Becoming over-protective of surviving children, and fearing them becoming sick and dying, was confirmed by four of the participants in this study.

Worden (2003), in his fourth task of mourning (emotionally relocating the deceased and moving on with life), explains learning to live with the loss, as finding a way of continuing bonds with loved ones that does not preclude the bereaved from going on with life. Kubler-Ross (1969, 1974, 2005), in her fifth and final stage of the grieving process (acceptance), highlights that learning to live with the loss now becomes the new norm or the new permanent reality. Similarly, acceptance involves remaining connected to the deceased by remembering them, in conjunction with reinvesting energy into life and new meaningful relationships. All of the participants reported learning to live with the loss that is memorializing or remembering the deceased, whilst investing emotional energy into life and other meaningful relationships.

4.9 Individualistic nature of the grieving process

Lastly, all of the participants stress the individualistic and personal nature of the grieving process, which bereaved mothers describe as a non-linear process, occurring cyclically for years after the loss with alternating periods of intensification, especially during birthdays or anniversaries. One participant, who is an avid reader, said that she would have literally gone crazy if she continuously compared herself to the classic stages set out in the bereavement literature. She reported grieving in her own way, and at her own pace, that felt right for her. Another participant asserted feeling sadder now than in the first years after losing her daughter. Her feelings of sadness seem to be connected to the lost expectations of what her daughter might have done with her life, and the person that she would have become in later life. One other participant spoke about not wanting to move away from the actual day and date of her son dying because she felt that she was getting further and further away from not only having been with him but also from him having been part of her life.

Participant 1: *"...I'm more sad now than in the first years of her loss...maybe with time, settling down you see what is missing, so it's not just a person that's missing, it's everything that goes with that person...the husband, the husband...everything. What would she have been like today? She would have been forty. What would she have achieved? She was definitely on her way up hey."*

Participant 2: *"...I don't know when a person can know when they are finished with grief, if there is such a thing, as finishing with it. All the theory...acceptance, bargaining, anger...I don't believe that it starts here and ends there. I think it goes back and forth at different times. I really do."*

Participant 3: *"...the love you feel for that child is so enormous...when they've gone and died...you don't want to move away from the date that you lost them, the actual day...cos you are getting further and further away from actually having been with them...you resent the sun and the moon turning around because you are further away from them having been part of your life. The bond is so all-consuming...the loss, the actual loss of going back to the bedroom...to the nursery...you would do anything just to feel him again...and you smell their clothes...you keep looking for them...that pain...it's..."*

Participant 8: *"Having read a lot of books on grief and loss and death and sickness and whatever trauma you are going through, I didn't go through the classic stages. Whether it was denial or a sense of knowing that I am sure I can cope, I don't know, but I did cope...So maybe I am just one out of, I don't know how many, who didn't blame God and should have...If I am going to govern myself by saying 'oh my god, I am at this stage of the grieving process- I have to be like this but I am not like that, then I am going to go cuckoo.'...So I dealt with it in my way."*

According to Rosenblatt (1988), models of the grieving process may be overly simplistic. Loss and bereavement are at once highly personal, socially determined and complex. There is no single human response to loss but instead a range of different responses. Kubler-Ross (1969, 1974, 2005) clearly states that not everyone will go through all five

stages of the grieving process, that is, denial, anger, bargaining, depression, acceptance, and that these stages do not follow a prescribed linear order. Similarly, Worden (2003) also emphasizes that the four tasks of mourning are revisited and reworked intermittently over time and that various tasks can be worked on simultaneously. Thus, grieving is a fluid, non-linear process, and symptoms may return for years after the loss (Hartz, 1986). Bereavement may take many forms and the extent to which it is adaptive or maladaptive can only be determined on an individual basis (Becvar, 2001), not by successful progression through a specific sequence of phases, tasks or stages (Neimeyer, 2001). All of the participants talked about grieving in their own way and at their own pace, rarely following a neat linear process, instead moving back and forth in the grieving process at different times in their lives, with no specific end-point.

Worden (2003) maintains that grieving is completed when the bereaved can reinvest his or her emotions into life and in living, as well as finding an appropriate place for the deceased that allows the mourner to remain connected with loved ones. All of the participants have managed to find alternate and unique ways of continuing bonds with their deceased children, and at the same time reinvesting emotional energy into life, living and meaningful relationships.

4.10 Summary

The findings from this study demonstrate that bereaved mothers find meaning in, and cope after, the loss of a child to cancer in the following ways. First, they find ways to remain connected with the deceased child. This manifests through talking about the child, remembering and internalizing the child, keeping the memory of the child 'alive,' maintaining contact with the child's friends and/or partners and child's friends parents, and displaying photos and portraits, or watching videos/films of the child.

A second finding highlights the importance of maintaining contact with people and/or organizations. This includes surviving children, grandchildren, spouse or partner, family members, friends, other bereaved parents, staff from the hospital, and professional organizations. Participants also make meaning, and cope after, a loss of a child to cancer

by engaging in fulfilling activities. This involves doing general volunteer work or volunteer work connected with the child, as well as pursuing a career associated with the child, and helping or educating other bereaved parents.

The next main finding illustrates changes in spiritual and/or religious beliefs. This incorporates belief in an afterlife or reunion with the child, belief in a greater scheme or bigger picture, faith in a higher power, believing that the death is some form of punishment, being more spiritual than religious, believing less or not at all in God/religion, and strengthened religious beliefs.

Moreover, participants talked about the benefit of seeking professional help during the palliative phase, as well as post-loss. Many participants confirmed that ongoing professional help whether it be individual psychotherapy or group support counselling, assisted them in adjusting to, and coping with, the loss of their child.

Another finding highlights positive psychological growth from losing a child. This encompasses reorganized values, viewing the death in perspective, appreciating people and life and the little things in life, and becoming a more caring, compassionate and stronger person.

Findings indicate that parental bereavement encompasses numerous complexities. This embodies the senselessness, and unnaturalness of the death of a child, as well as the effect that an expected death of a child has on bereaved mothers.

Another finding emphasizes the ongoing difficulties that bereaved mother's experience. This involves becoming over-protective and/or fearing the death of surviving children, neglecting or being unavailable to surviving children and the effect that this has on surviving children in later life, and learning to live with the loss.

A final theme that emerged from this study is the individualistic nature of the grieving process, which all participants describe as not only personal, but also non-linear and cyclical.

The chapter that follows integrates the findings with existing literature, and discusses implications for future research and practice.

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CHAPTER FIVE

CONCLUSION

The chapter begins with a summary of the main findings generated. Thereafter, the limitations and significance of the present study are discussed. Finally, the implications of the findings for future research and clinical practice are highlighted.

5.1 *Summary of Main Findings*

The results or findings from this particular study challenge the basic tenets of Freud's 'grief work' approach, and instead contribute to the emerging bereavement literature focusing on how bereaved mothers make sense of, and cope, in the aftermath of losing a child to cancer.

Grounded theory data analysis indicated that all of the participants in this study found it meaningful to memorialize or remember their children in varying ways, and to continue the bond with their deceased children in a manner that did not prohibit them from reinvesting in life, living, and relationships. Participants were able to maintain a simultaneous attachment to both the living and to the deceased. More specifically, this was achieved through remaining connected to the child who has died. The most cited ways, for all of the participants, of remaining connected to their deceased children are to talk about their children with other people, and to display photographs in their home or at work. Thus, the grieving and meaning-making process is not about severing the bond with the deceased, as originally postulated by Freud (1917/1957), but rather redefining the relationship with the deceased in a way that ensures continuity, and makes life meaningful for the bereaved.

Another finding is that the grieving process is not private and intrapsychic, but deeply social, relational and intersubjective. The significant and integral role of relationships and the social milieu must be recognised and emphasized in the grieving process, as meaningful connections may facilitate recovery from parental bereavement. All of the participants, in one form or another, reported finding meaning in having contact with

various people and organizations. Many participants mentioned the importance of having contact with other bereaved parents, as it helps them feel less lonely and isolated in their grief. All of the participants cited having contact with surviving children as meaningful. For most of the participants, surviving children gave them not only a reason to live but also the strength to continue with life. Linked to the notion of grief being profoundly social and relational is the theme of fulfilling activities. More than half of the participants talked about either pursuing a career or doing volunteer work connected to the deceased child, or doing volunteer work in general as a way of giving back to the community. Therefore, it seems that contributing to society, and giving of oneself to others, not only assists many participants in adjusting to, and coping with, child death but also makes life meaningful, worthwhile and fulfilling for them. Half of the participants also found, and some still continue to find, benefit in seeking professional help during the palliative phase and post-loss.

Most importantly, adjustment and/or recovery from losing a child to cancer may take many forms, and the extent to which it is adaptive or maladaptive can only be determined on an individual basis, and not by successful progression through a specific series of phases or stages. A myriad of themes generated from the data, such as changes in religious and/or spiritual beliefs, positive psychological growth from the trauma, complexities surrounding parental bereavement, ongoing difficulties that bereaved mothers endure, and the individualistic nature of the grieving process, all clearly illustrate the uniqueness of the grief experience, in the following ways.

With regard to the theme of changes in religious and/or spiritual beliefs, results were mixed. Five participants reported strengthened religious beliefs, whereas the other five participants asserted believing even less in religion and becoming more spiritual, post-loss. Religious beliefs or faith in religion prior to the loss were instrumental in changes in religious and/or spiritual beliefs, after the loss.

With regard to the theme of positive psychological growth from the trauma, one participant, for example talked about perceived growth in certain domains and not in

others. On the one hand, she stated becoming more aggressive and cynical about life but on the other hand, more confident within herself and more outgoing in general. Another participant described herself as becoming more negative in general yet developing a very soft spot for animals and nature, after having lost her daughter. Therefore, positive psychological growth seems to be not only individually based, but also may occur in one area and not in others.

Furthermore, the effect that an expected death has on bereaved mothers, which fell under the theme of complexities surrounding parental bereavement, also demonstrated mixed results. Three participants found witnessing their child die slowly extremely painful and difficult, whereas another three participants were grateful that they had the preparatory time prior to the loss. Another sub-theme under the main theme of complexities surrounding parental bereavement, which creates ambivalence, is the senselessness and unnaturalness of child death. Interestingly, many of the participants were still unable to answer the question, 'why does a child have to die?' but had nonetheless found some renewed purpose in life.

Within the theme of ongoing difficulties that bereaved mothers endure, under the sub-theme of becoming over-protective and/or fearing the death of surviving children, results were once again mixed. Four participants reported experiencing this whilst others did not.

Lastly, the theme highlighting the individualistic nature of the grieving process strongly emphasizes that grief is highly personal and individually defined. Participants explain that the mourning process is non-linear and very often does not follow standard characteristics of theoretical models indicated in the bereavement literature. For example, one participant reported feeling more sad now, thirteen years after the loss of her daughter, than during the initial years, whilst other participants stated that they either did not pass through the classic stages of grief or could not understand the concept of the mourning process being completed or finished, as in her experience, grief-related symptoms occur cyclically with no end-point.

South African bereaved mothers in this study display similar bereavement processes to those sampled in international literature. These bereavement processes highlight the importance of remembering and remaining connected to the deceased, as well as the integral role of relationships and meaningful connections. In addition, each bereavement process is unique and adjustment post-loss can only be determined on an individual basis.

5.2 Limitations of Study

The researcher used a small sample in which the participants came from relatively the same socio-economic group, and were homogenous in sex. For this reason, the study does not intend to yield conclusive results and cannot be generalized to the wider community or to diverse populations. In addition, the participants interviewed are likely to have particular characteristics; for example, being more resilient and less depressed, as snowball sampling was employed. However, the researcher decided to use this sampling method in order to reduce risk to the participants in this sensitive area of research.

5.3 Significance of Study

Despite the above-mentioned limitations, rich meaningful data was gathered during the interviews and the findings contribute not only to the limited existing body of empirical literature but also to current theoretical models of the bereavement process, which do not adequately incorporate the concept of meaning-making. It is hoped that this study will also benefit those working with bereaved parents, for example, various mental health professionals and health-care workers, in so far as it might suggest ways in which therapists can facilitate the process of meaning-making at later stages in the therapy process. Lastly, more empirical studies need to be generated on parental bereavement, particularly within the South African population. The present study aims to begin to address this absence.

5.4 Implications of Findings for Future Research and Clinical Practice

Health-care workers and mental health professionals working in the field of loss and bereavement could be more cognizant of a number of issues pertaining not only to the grieving process but also particularly related to mothers losing a child to cancer, which

differs from other types of parental bereavement. The first issue focuses on the complicated and complex nature of parental bereavement. With regard to parental bereavement, the natural order of life and death is undermined, prior meaning structures and fundamental assumptions about the world are deeply and profoundly shaken, and bereaved mothers' present with an ongoing struggle in learning to live with the unanswered question of why a child has to die.

Second, participants reported that losing a child to a malignant disease such as cancer, which very often follows a progressively deteriorating course, causes distress in itself, as they slowly witnessed a loved one die from an extended illness. Moreover, child death due to cancer invariably creates role-strain for mothers during the palliative phase, and also has a long-term effect on immediate familial relationships, that is, spouse or partner, and surviving children.

Lastly, and most importantly, health-care workers and mental health professionals need to recognise, and take into account, the individualistic and personal nature of the grieving process, which bereaved mothers might or might not go through, as well as the range of possible reactions to losing a child. This study clearly demonstrates that bereaved mothers seem to create their own personal meaning from their loss, for example by having contact with people and/or organizations, occupying their time with fulfilling activities, modifying or changing their religious and/or spiritual beliefs, seeking professional help, and perceiving themselves as positively growing from the trauma. Bereaved mothers also have a strong desire to want to remain connected to their deceased children in a way that is meaningful and healthy for them.

Forcing the bereaved into a specific theoretical model of mourning, or even viewing the grieving experience as a predictable series of stages may prove to be extremely harmful, stifling, insensitive and inappropriate. Thus, the acknowledgement of individual differences in the process of mourning leads to a critical question: What constitutes a pathological grief reaction? The current research findings suggest that movement toward adaptation, and recovery from a significant loss, can perhaps only be determined on an

individual basis, which is assessed by the specific context of a person's life, rather than by absolute guidelines and abstract models.

Therefore, after careful consideration of the range of themes that emerged in the present study, and the mixed results that arose within sub-themes of most themes, the researcher proposes that theoretical models of grieving such as those conceived by Worden (2003) and Kubler-Ross (2005), be used loosely as a guiding framework, which is then fleshed out by the griever.

Although the grieving process is different and distinct from the meaning-making process, they are interrelated. The former (grieving process) is about acceptance of the loss and working with the feelings associated around losing a loved one. The latter (meaning-making process) is about finding meaning in the loss, and finding meaning involves two major components. The first component is cognitive mastery (meaning-as-comprehensibility), and the second is renewed purpose (meaning-as-significance). However, many participants in this study illustrate that renewed purpose in life can be achieved without necessarily having made sense of, or having specific answers to, certain questions surrounding the comprehensibility of losing a child to a malignant disease, such as cancer.

“A doctor once asked me, ‘if you could have chosen to have your daughter knowing she would die while still young, would you still have had her?’ and my answer was, ‘of course I would have had her, she gave us so much pleasure.’”

(Participant 4, 2006)

REFERENCES

- Adler, M.G., & Fagley, N.S. (2005). Appreciation: Individual differences in finding value and meaning as a unique predictor of subjective well-being. *Journal of Personality*, 73(1), 79-114.
- Affleck, G., & Tennen, H. (1996). Construing benefits from adversity: Adaptational significance and dispositional underpinnings. *Journal of Personality*, 64, 899-922.
- Attig, T. (1996). *How we grieve: Relearning the world*. New York: Oxford University Press.
- Bailey, B.J., & Gregg, C.H. (1986). Grief, pathological grief, and rehabilitation counseling. *Journal of Applied Rehabilitation Counseling*, 17(4), 19-23.
- Barlow, D.H., & Durand, V.M. (1999). *Abnormal psychology: An integrated approach*. (2nd ed.). Pacific Grove: Brooks/Cole.
- Barr, P. (2004). Guilt- and shame -proneness and the grief of perinatal bereavement. *Theory, Research and Practice*, 77(4), 493-510.
- Becvar, D.S. (2001). *In the presence of grief: Helping family members resolve death, dying and bereavement issues*. New York: Guilford Press.
- Benore, E.R., & Park, C.L. (2004). Death-specific religious beliefs and bereavement: Belief in an afterlife and continued attachment. *International Journal for the Psychology of Religion*, 14(1), 1-22.
- Bernstein, J.R. (1997). *When the bough breaks: Forever after the death of a son or daughter*. Kansas City, MO: Andrews & McKeel.
- Birenbaum, L.K., Stewart, B.J., & Philips, D.S. (1994). Health status of bereaved parents. *Nursing Research*, 45(2), 105-109.
- Bohannon, J.R. (1990). Grief responses of spouses following the death of a child: A longitudinal study. *Omega*, 22, 109-121.
- Bonanno, G.A. (2004). Loss, trauma, and human resilience: Have we underestimated the human capacity to thrive after extremely aversive events? *American Psychologist*, 59(1), 20-28.
- Bonanno, G.A., & Kaltman, S. (1999). Toward an integrative perspective on bereavement. *Psychological Bulletin*, 125, 760-776.
- Bowlby, J. (1969). *Attachment and loss: Attachment* (Vol. I). New York: Basic Books.
- Bowlby, J. (1980). *Attachment and loss: Loss, sadness and depression*. (Vol III). New York: Basic Books.
- Bosticco, C., & Thompson, T.L. (2005). Narratives and story telling in coping with grief and bereavement. *Omega, Journal of Death and Dying*, 51(1), 1-16.
- Braun, M.J., & Berg, D.H. (1994). Meaning reconstruction in the experience of parental bereavement. *Death Studies*, 18, 105-129.
- Breakwell, G.M., Hammond, S., & Fife-Schaw, C. (1995). *Research methods in psychology*. London: Sage Publications.
- Cardella, L.A., & Friedlander, M.L. (2004). The relationship between religious coping and psychological distress in parents of children with cancer. *Journal of Psychosocial Oncology*, 22(1), 19-37.
- Cavanaugh, J.C., & Blanchard-Fields, F. (2002). *Adult development and aging* (4th ed.). London: Wadsworth.

- Charmaz, K. (2000). Grounded theory: Objectivist and constructivist methods. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 509-535). Thousand Oaks, CA: Sage.
- Chodoff, P., Friedman, S.B., & Hamburg, D.A. (1964). Stress, defenses and coping behaviour: Observations in parents of children with malignant disease. *American Journal of Psychiatry*, 120, 743-749.
- Clarke, S., Davies, H., Jenney, M., Glaser, A., & Eiser, C. (2005). Parental communication and children's behaviour following diagnosis of childhood leukaemia. *Psycho-Oncology*, 14(4), 274-281.
- Clerici, C.A., Ferrari, A., Massimino, M., Luksch, R., Cefalo, G., Terenziani, M., Polastri, D., Meazza, C., Podda, M., & Fossati-Bellani, F. (2006) Assistance to parents who have lost their child to cancer. *Tumori*, 92(4), 306-310.
- Cochran, L., & Claspell, E. (1987). *The meaning of grief*. New York: Greenwood Press.
- Coleman, P.G., Ivani-Chalian, C., & Robinson, M. (2004). Religious attitudes among british older people: Stability and change in a 20-year longitudinal study. *Ageing and Society*, 24(2), 167-188.
- Cook, J.A. (1983). A death in the family: Parental bereavement in the first year. *Suicide and Life-Threatening Behaviour*, 13, 42-61.
- Cook, A.S., & Dworkin, D.S. (1992). *Helping the bereaved*. New York: Harper Collins Publishers.
- Corbin, J. (1986). Qualitative data analysis for grounded theory. In W.C. Chenitz & J.M. Swanson (Eds.), *From practice to grounded theory: Qualitative research in nursing* (pp. 91-101). Menlo Park, CA: Addison Wesley.
- Davis, C.G., Nolen-Hoeksema, S., & Larson, J. (1998). Making sense of loss and benefiting from the experience: Two construals of meaning. *Journal of Personality and Social Psychology*, 75(2), 561-574.
- Dean, M., McClement, S., Bond, J.B., Daeninck, P.J., & Nelson, F. (2005). Parental experiences of adult child death from cancer. *Journal of Palliative Medicine*, 8(4), 751-765.
- Deits, B. (2000). *Life after loss: A personal guide dealing with death, divorce, job change and relocation*. (3rd ed.). USA: Fisher Books.
- Demi, A., & Miles, M. (1987). Parameters of normal grief: A delphi study. *Death Studies*, 11, 397-412.
- Doka, K.J., & Davidson, J.D. (1998). *Living with grief, who we are and how we grieve*. Washington, DC: Hospice Foundation of America.
- Dorpat, T.L. (1973). Suicide, loss, and mourning. *Life-Threatening Behaviour*, 3, 213-224.
- Doran, G., & Hansen, N. (2006). Constructions of Mexican American family grief after the death of a child: An exploratory study. *Cultural Diversity and Ethnic Minority Psychology*, 12(2), 199-211.
- Drew, D., Goodenough, B., Maurice, L., Foreman, T., & Willis, L. (2005). Parental grieving after a child dies from cancer: Is stress from stem cell transplant a factor? *International Journal of Palliative Nursing*, 11(6), 266-273.
- Ellifritt, J., Nelson, K.A., & Walsh, D. (2003). Complicated bereavement: A national survey of potential risk factors. *American Journal of Hospice and Palliative Care*, 20(2), 114-120.

- Fairbairn, W.D. (1952). *An object-relations theory of the personality*. New York: Basic Books.
- Figley, C.R., Bridge, B.E., & Mazza, N. (1997). *Death and trauma: The traumatology of grieving*. Washington, DC: Taylor & Francis.
- Fish, W. (1986). *Parental loss of a child*. Champaign, IL: Research Press.
- Fulton, R. (1987). The many faces of grief. *Death Studies*, 11, 243-256.
- Frankl, V.E. (1978). *The unheard cry for meaning: An introduction to logotherapy*. New York: Simon & Schuster.
- Frankl, V.E. (1986). *Man's search for meaning: An introduction to logotherapy* (3rd ed.). New York: Simon & Schuster.
- Freud, S. (1957). *Mourning and melancholia*. Standard Edition. (Vol. XIV, 1917). London: Hogarth.
- Gardiner, A., & Pritchard, M. (1977). Mourning, mummification, and living with the dead. *British Journal of Psychiatry*, 130, 23-28.
- Geller, J.L. (1985). The long-term outcome of unresolved grief: An example. *Psychiatry Quarterly*, 57(2), 142-146.
- Glaser, B.G., & Strauss, A.L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. London: Weidenfeld & Nicolson.
- Glick, I.O., Weiss, R.S., & Parkes, C.M. (1974). *The first year of bereavement*. New York: Wiley.
- Goalder, J.S. (1985). Morbid grief reaction: A social systems perspective. *Professional Psychology: Research and Practice*, 16(6), 833-842.
- Gorer, G.D. (1965). *Death, grief and mourning*. New York: Doubleday.
- Hartz, G.W. (1986). Adult grief and its interface with mood disorder. Proposal of a new diagnosis of complicated bereavement. *Comprehensive Psychiatry*, 27(1), 60-64.
- Harvey, J.H., Orbuch, T.L., Chwalisz, K.D., & Garwood, G. (1991). Coping with sexual assault: The roles of account-making and confiding. *Journal of Traumatic Stress*, 4, 515-531.
- Herman, J.L. (1992). *Trauma and recovery*. London: Pandora.
- Hogon, N., Morse, J., & Tason, M. (1996). Toward an experiential theory of bereavement. *Omega*, 33, 43-65.
- Horowitz, M.J. (1990). A model of mourning: Change in schemas of self and other. *Journal of American Psychoanalytic Association*, 38(2), 297-324.
- Horowitz, M.J., Wilner, N., Marmar, C., & Krupnick, J. (1980). Pathological grief and the activation of latent self images. *American Journal of Psychiatry*, 137, 1157-1162.
- Horowitz, M.J., Siegel, B., Holen, A., Bonanno, G.A., Milbrath, C., & Stinson, C.H. (1997). Diagnostic criteria for complicated grief disorder. *American Journal of Psychiatry*, 154, 904-910.
- Humphrey, G.M., & Zimpfer, D.G. (1996). *Counseling for grief and bereavement*. Thousand Oaks, California: Sage Publications.
- James, R.K., & Gilliland, B.E. (2001). *Crisis intervention strategies* (4th ed.). Pacific Grove, California: Brooks Cole Publishing.
- Janoff-Bulman, R. (1992). *Shattered assumptions: Towards a new psychology of trauma*. New York: Free Press.

- Janoff-Bulman, R., & McPherson Frantz, C. (1997). The impact of trauma on meaning: From meaningless world to meaningful life. In M. Power, & C.R. Brewin (Eds.), *The transformation of meaning in psychological therapies: Integrating theory and practice* (pp. 91-106). New York: Wiley.
- Kalish, R.A. (1981). *Death, grief and caring relationships*. Monterey, CA: Brooks/Cole.
- Kastenbaum, R.J. (1986). *Death, society, and human experience* (3rd ed.). Columbus, OH: Charles E. Merrill.
- Kazdin, A.E. (1981). Drawing valid inferences from case studies. *Journal of Consulting and Clinical Psychology*, 49, 183-192.
- Kernberg, O.F. (1976). *Object-relations theory and clinical psychoanalysis*. New York: Aronson.
- Klass, D. (1999). *The spiritual lives of bereaved parents*. Philadelphia: Brunner/Mazel.
- Klass, D., Silverman, P., & Nickman, S. (Eds.). (1996). *Continuing bonds: New understandings of grief*. Washington, DC: Taylor & Francis.
- Koocher, G.P. (1986). Coping with a death from cancer. *Journal of Consulting and Clinical Psychology*, 54(5), 623-631.
- Kreicbergs, U. (2004). Anxiety and depression in parents 4-9 years after the loss of a child owing to a malignancy: A population-based follow-up. *Psychological Medicine*, 34(8), 1431-1441.
- Kubler-Ross, E. (1969). *On death and dying*. New York: Macmillan.
- Kubler-Ross, E. (1974). *Questions and answers on death and dying: Answers the most frequently asked questions about death*. New York: Macmillan.
- Kubler-Ross, E. (2005). *On grief and grieving: Finding the meaning of grief through the five stages of loss*. Great Britain: Simon & Schuster.
- Kushner, H. S. (1982). *When bad things happen to good people*. Great Britain: Pan Books.
- Lambrinidou, Y. (2000). Joey court: Death of a child. In A. Towers, & D. Barnard, *Crossing over: Narratives of palliative care* (pp. 355-376). London: Oxford University Press.
- Li, J., Laursen, T.M., Precht, D.H., Olsen, J., & Mortensen, P.B. (2005). Hospitalization for mental illness among parents after the death of a child. *Journal of Medicine*, 352(12), 1190-1196.
- Linley, P.A. & Joseph, S. (2004). Positive change following trauma and adversity: A review. *Journal of Traumatic Stress*, 17(1), 11-21.
- Littlefield, C.H., & Rushton, J.P. (1986). When a child dies: The sociobiology of bereavement. *Journal of Personality and Social Psychology*, 51(4), 797-802.
- Macnab, F. (1989). *Life after Loss*. Alexandria, New South Wales: Millenium Books.
- Malkinson, R., & Bar-Tur, L. (2004). Long term bereavement processes of older parents: The three phases of grief. *Journal of Death and Dying*, 50(2), 103-129.
- McIntosh, D.N., Silver, R.C., & Wortman, C.B. (1993). Religion's role in adjustment to a negative life event: Coping with the loss of a child. *Journal of Personality and Social Psychology*, 65(4), 812-821.
- McMenamy, J., & Perrin, E.C. (2003). In the eyes of the beholder: Resilience or repression? *Families, Systems and Health*, 21(3), 277-279.

- Miles, M.S., & Crandall, E.K.B. (1983). The search for meaning and its potential for affecting growth in bereaved parents. *Health Values: Achieving High Level Wellness*, 7, 19-23.
- Miles, M.S., & Demi, A.S. (1984). Toward the development of bereavement guilt: Sources of guilt in bereaved parents. *Omega*, 14, 299-314.
- Miles, M.S. (1985). Emotional symptoms and physical health in bereaved parents. *Nursing Research*, 34, 76-81.
- Miles, M.B., & Huberman, A.M. (1994). *Qualitative data analysis: An expanded sourcebook*. Thousand Oaks: Sage.
- Monterosso, L., deCinque, N., Dadd, G., Sidhu, R., Macpherson, R., & Aoun, S. (2006). Bereavement support for families following the death of a child from cancer: Experience of bereaved parents. *Journal of Psychosocial Oncology*, 24(2), 65-83.
- Moore, I.M., Gilliss, C.L., & Martinson, I. (1988). Psychosomatic symptoms in parents 2 years after the death of a child from cancer. *Nursing Research*, 37, 104-107.
- Moos, R.H., & Schaefer, J.A. (1986). Life transitions and crises: A conceptual overview. In R.H. Moos (Ed.), *Coping with life crises: An integrated approach* (pp. 3-28). New York: Plenum Press.
- Morris, B.A., Shakespeare-Finch, J., Rieck, M., & Newbery, J. (2005). Multidimensional nature of posttraumatic growth in an Australian population. *Journal of Traumatic Stress*, 18(5), 575-585.
- Morrow, G.R., Hoagland, A., & Carnrike, C.L.M. (1981). Social support and parental adjustment to pediatric cancer. *Journal of Consulting and Clinical Psychology*, 49(5), 763-765.
- Neimeyer, R. (1998). *The lessons of loss: A guide to coping*. New York: McGraw-Hill.
- Neimeyer, R.A. (2001). *Meaning reconstruction and the experience of loss*. Washington: American Psychological Association.
- Newman, E., & Kaloupek, D.G. (2004). The risks and benefits of participating in trauma-focused research studies. *Journal of Traumatic Stress*, 17(5), 383-394.
- Nisbett, R.E., & Ross, L. (1980). *Human inference: Strategies and shortcomings in social judgement*. New York: Century.
- Norris, F.N., & Murrell, S.A. (1987). Older adult family stress and adaptation before and after bereavement. *Journal of Gerontology*, 42, 606-612.
- O'Leary, J. (2004). Grief and its impact on prenatal attachment in the subsequent pregnancy. *Archives of Woman's Mental Health*, 7(1), 7-18.
- Osterweis, M., Solomon, F., & Green, M. (1984). *Bereavement: Reactions, consequences and care*. Washington, DC: National Academy Press.
- Parkes, C.M. (1970). The first year of bereavement: A longitudinal study of the reaction of London widows to death of husbands. *Psychiatry*, 33, 444-467.
- Parkes, C.M. (1972). *Bereavement: Studies of grief in adult life*. New York: International University Press.
- Parkes, C.M. (1975). Determinants of outcome following bereavement. *Omega*, 6, 303-323.
- Parkes, C.M. (1988). Bereavement as a psychosocial transition: Processes of adaptation to change. *Journal of Social Issues*, 44(3), 53-65.
- Parkes, C.M., & Weis, R.S. (1983). *Recovery from bereavement*. New York: Basic Books.

- Peretz, D. (1970). *Loss and grief*. New York: Columbia University Press.
- Rando, T.A. (1986). *Parental loss of a child*. Champaign, IL: Research Press.
- Rando, T.A. (1993). *Treatment of complicated mourning*. Champaign, IL: Research Press.
- Rando, T.A. (1997). *Death and trauma: The traumatology of grieving*. Washington, DC: Taylor & Francis.
- Raphael, B. (1983). *The anatomy of bereavement*. New York: Basic Books.
- Robinson, W.D., Carroll, J.S., & Watson, W.L. (2005). Shared experience building around the family crucible of cancer. *Families, Systems and Health*, 23(2), 131-147.
- Rosen, F.J. (1988). Family therapy in cases of interminable grief for the loss of a child. *Omega*, 19, 187-201.
- Rosenblatt, P.C. (1988). Grief: The social context of private feelings. *Journal of Social Issues*, 44(3), 67-78.
- Rowe, D. (1983). Constructing life and death. *Death Education*, 7(2-3), 97-113.
- Rubin, S.S. (1984). Mourning distinct from melancholia: The resolution of bereavement. *British Journal of Medical Psychology*, 57, 339-345.
- Russac, R.J., Steighner, N.S., & Canto, A.I. (2002). Grief work versus continuing bonds: A call for paradigm integration or replacement? *Death Studies*, 26(6), 463-478.
- Ryneerson, E.K. (1987). Psychotherapy of pathological grief: Revisions and limitations. *Psychiatric Clinics of North America*, 10(3), 487-499.
- Saakvitne, K.W., Tennen, H., & Affleck, G. (1998). Exploring thriving in the context of clinical trauma theory: Constructivist self-development theory. *Journal of Social Issues*, 54, 279-299.
- Sanders, C.M. (1980). A comparison of adult bereavement in the death of a spouse, child and parent. *Omega*, 10, 303-322.
- Sanders, C.M. (1982). Effects of sudden vs chronic illness death on bereavement outcome. *Omega*, 13(3), 227-241.
- Sanders, C. (1999). *Grief, the mourning after: Dealing with adult bereavement* (2nd ed.). New York: Wiley.
- Schuchter, S.R. (1986). *Dimensions of grief: Adjusting to the death of a spouse*. San Francisco: Jossey-Bass.
- Schut, H.A.W., Stroebe, M.S., & van den Bout, J. (1997). Intervention for the bereaved: Gender differences in the efficacy of two counselling programmes. *British Journal of Clinical Psychology*, 36, 63-72.
- Schwab, R. (1996). Gender differences in parental grief. *Death Studies*, 20, 103-113.
- Schwartzberg, S.S., & Halgin, R.P. (1991). Treating grieving clients: The importance of cognitive change. *Professional Psychology: Research and Practice*, 22(3), 240-246.
- Shapiro, E. (1996). Grief in Freud's life: Reconceptualizing bereavement in psychoanalytic theory. *Psychoanalytic Psychology*, 13, 547-566.
- Silverman, P.R., & Klass, D. (1996). *Continuing bonds: New understandings of grief*. Washington, DC: Taylor and Francis.
- Simons, B.G. (1979). *A time to grieve: Loss as a universal human experience*. New York: Family Service Association of America.
- Staudacher, C. (1987). *Beyond grief: A guide for recovering from the death of a loved one*. Canada: Raincoast Books.

- Stake, R.E. (2000). Chapter 16: Case studies. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 435-454). Thousand Oaks, CA: Sage.
- Stolorow, R., & Atwood, G. (1992). *Contexts of being: The intersubjective foundations of psychological life*. Hillsdale, NJ: Analytic Press.
- Strauss, A.L., & Corbin, J. (1990). *Basics of qualitative research*. Newbury Park, CA: Sage.
- Stroebe, M.S., & Stroebe, W. (1987). *Bereavement and health*. Cambridge, England: Cambridge University Press.
- Stroebe, M.S., & Stroebe, W. (1989). Who participates in bereavement research: A review and empirical study. *Omega*, 20, 1-29.
- Stroebe, M.S., & Stroebe, W. (1991). Does "grief work" work? *Journal of Consulting and Clinical Psychology*, 59, 479-482.
- Stroebe, M., Stroebe, W., Gergen, K.J., & Gergen, M.M. (1992). Broken hearts or broken bonds: Love and death in historical perspective. *American Psychologist*, 47(10), 1205-1212.
- Stroebe, M. (1992). Coping with bereavement: A review of the grief work hypothesis. *Omega*, 26, 19-42.
- Stroebe, M.S., Stroebe, W., & Schut, H. (2001). Gender differences in adjustment to bereavement: An empirical and theoretical review. *Journal of Psychology*, 5(1), 62-83.
- Strydom, H., Fouche, C.B., & Delport, C.S.L. (2002). *Research at grass roots: For the social sciences and human service professionals*. (2nd ed.). Pretoria: Van Schaik Publishers.
- Tatelbaum, J. (1997). *The courage to grieve: Creative living, recovery and growth through grief*. London: Random House.
- Taylor, S.E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. *American Psychologist*, 38(1), 1161-1173.
- Tedeschi, R.G., & Calhoun, L.G. (1995). *Trauma and transformation: Growing in the aftermath of suffering*, Chapter 3: Psychological growth from trauma- research findings (pp. 29-41). Thousand Oaks: Sage.
- Tedeschi, R.G., & Calhoun, L.G. (2004). The foundations of posttraumatic growth: New considerations. *Psychological Inquiry*, 15(1), 93-102.
- Terre Blanche, M., & Kelly, K. (1999). Interpretive research. In M. Terre Blanche & K. Durrheim (Eds.), *Research in practice: Applied methods for the social sciences*. Cape Town: UCT Press.
- Thompson, S.C. (1981). Will it hurt less if I can control it? A complex answer to a simple question. *Psychological Bulletin*, 90(1), 89-101.
- Videka-Sherman, L. (1982). Coping with the death of a child: A study over time. *American Journal of Orthopsychiatry*, 52, 688-698.
- Volkan, V. D. (1985). Complicated mourning. *Annals of Psychoanalysis*, 12, 323-348.
- Worden, J.W. (1991). *Grief counselling and grief therapy* (2nd ed.). London: Brunner-Routledge.
- Worden, J.W. (2003). *Grief counselling and grief therapy: A handbook for the mental health practitioner* (3rd ed.). London: Brunner-Routledge.
- Wheeler, I. (2001). Parental bereavement: The crisis of meaning. *Death Studies*, 25(1), 51-66.

- Wing, D.G., Burge-Callaway, K., Clance, P.R., & Armistead, L. (2001). Understanding gender differences in bereavement following the death of an infant: Implications for treatment. *Journal of Clinical Psychology*, 38(1), 60-74.
- Wortman, C.B., & Silver, R.C. (1989). The myths of coping with loss. *Journal of Consulting and Clinical Psychology*, 57, 349-357.
- Young, B., Dixon-Woods, M., Findlay, M., & Heney, D. (2002). Parenting in a crisis: Conceptualizing mothers of children with cancer. *Social Science and Medicine*, 55(10), 1835-1847.
- Zaiger, N. (1985). Woman and bereavement. *Woman and therapy*, 4, 33-43.
- Zoellner, T., & Maercker, A. (2006). Posttraumatic growth in clinical psychology: A critical review and introduction of a two component model. *Clinical Psychology Review*, 26, 626-653.
- Zisook, S., & DeVaul, R. (1985). Unresolved grief. *The American Journal of Psychoanalysis*, 45(4), 370-379.
- Zisook, S., & Shuchter, S.R. (1993). Uncomplicated bereavement. *Journal of Clinical Psychiatry*, 54, 365-372.

APPENDICES

Appendix 1

INTERVIEW SCHEDULE

Section A

Name; age

Marital status; number of children?

Employment status

Living arrangements; who do you live with?

Religion; relationship with your religion? / religious beliefs?

Have you ever been in therapy or been treated by a psychiatrist? / for how long?

Section B

How long ago did your son/daughter die?

Age when son/daughter died?

How would you describe your son/daughter before he/she became sick?

When you initially found out that your son/daughter had cancer, what went through your mind?

Section C

Have you noticed any changes in yourself after the loss of your son/daughter?

Have there been any changes in your relationships with your partner, family and/or friends after the loss of your son/daughter?

Section D

How do you make sense of why this happens in life?

And particularly to you?

Where do you draw strength from in order to cope or manage with the loss of your son/daughter?

What were your assumptions/beliefs about yourself and the world before this happened as opposed to now?

How has this influenced the life that you lead now?

Section E

What are you still struggling with, what is still the hardest?

[Note: At the end of the interview, a reflective process was conducted.]

Appendix 2

CONSENT FORM

You are invited to participate in a study, which investigates how bereaved mothers make sense of, and cope after, the loss of a child to cancer. This research will help in understanding how bereaved mothers experience their loss and how they deal with it.

It is important to highlight that this study is voluntary. If you choose to participate, an interview consisting of several guiding questions will be conducted, which will last approximately ninety minutes. Recording equipment will be employed. There is a possibility that the interview process might be upsetting due to the subject matter, and participants have the right to stop the interview, or withdraw from the study, at any point. However, many people also find it useful and meaningful to be interviewed about difficult experiences they have been through.

The participants in this study will remain anonymous, and the recorded data will be kept confidential.

Date

Date

Signature of Participant **Signature of Researcher**